The World Health Organization Quality of Life (WHOQOL) Study

AUSTRALIAN WHOQOL-100, WHOQOL-BREF and CA-WHOQOL INSTRUMENTS

User's Manual and Interpretation Guide

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CHAPTER 1 - INTRODUCTION

PURPOSE OF THIS MANUAL

The purpose of this manual is to facilitate administration, scoring and interpretation of the Australian versions of the WHOQOL-100 and the WHOQOL-BREF. This manual contains information regarding the development of the WHOQOL instruments, both at an international and national level, details of the psychometric properties of the instruments, and guidelines for administration, scoring and interpretation, together with copies of the Australian WHOQOL instruments. This manual is specific to the Australian versions of the WHOQOL, including both the English versions (the *Australian WHOQOL-100* and the *Australian WHOQOL-BREF*) and Chinese-Australian version (the *CA-WHOQOL-100*).

Chapter 1 of this manual provides a brief summary of the WHOQOL instruments and broad guidelines for their use, while Chapter 2 provides an overview of the development of the WHOQOL instruments, providing both an international and a national perspective. Users of the Australian WHOQOL instruments are encouraged to read both of these introductory chapters by way of orientation to the WHOQOL Project and instruments. Users are then referred to the specific relevant chapter: the Australian WHOQOL-100 is discussed in Chapter 3, the Australian WHOQOL-BREF is discussed in Chapter 4, and the Chinese-Australian WHOQOL (CA-WHOQOL) is discussed in Chapter 5. Each chapter provides a description of the instrument, details of its psychometric properties, and guidelines for administration and scoring. Copies of the Australian WHOQOL-100 and the Australian WHOQOL-BREF are appendixed in this manual. A copy of the CA-WHOQOL can be obtained upon request from the Melbourne WHOQOL Field Study Centre.

This manual is complimented by a series of papers prepared by The WHOQOL Group and published in refereed journals. These papers are referred to where appropriate throughout this manual, and a generalised review of the papers is given in Chapter 2. Users of the Australian WHOQOL instruments are encouraged to access specific paper as required or desired. An annotated bibliography of the WHOQOL papers can be obtained upon request from the Melbourne WHOQOL Field Study Centre.

SUMMARY OF THE WHOQOL INSTRUMENTS

The WHOQOL-100 assesses individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It has been developed collaboratively and internationally, initially involving 15 centres worldwide and to date involving over 30 centres. It has now been field-tested in 37 field study centres worldwide. It is a 100-item instrument that currently exists in directly comparable forms in 29 language versions. It

yields a multi-dimensional profile of scores across domains and facets of quality of life (QOL). More recently, an abbreviated 26-item instrument, the WHOQOL-BREF, has been developed. This shorter version may be more convenient for researchers who are conducting large research studies or clinical trials.

The Australian-English versions of the WHOQOL-100 and the WHOQOL-BREF have been developed concurrently with other national versions of the WHOQOL but are specific to the Australian context. While they contain the same items as other national versions, the wording of some items has been altered to reflect customary language and to ensure cultural sensitivity. In addition, the response scales for all items were derived specifically for the Australian instruments using an Australian sample. The response scales have been designed to ensure comparability across different cultural versions of the WHOQOL.

While the Australian-English WHOQOL instruments have wide application, they may not necessarily be culturally relevant to all ethnic communities in Australia, and require an understanding of the English language. It is anticipated that new WHOQOL instruments will be developed for specific ethnic communities in Australia, in accordance with the WHOQOL Protocol for New Centres (WHO, 1994).

To date, the CA-WHOQOL-100 has been developed, being specific to the Chinese-Australian community. The CA-WHOQOL comprises a translated version of each WHOQOL-100 item, plus additional items relevant to the Chinese-Australian community. Again the response scales for all items were derived specifically for this instrument using a Chinese-Australian sample. The developmental process and potential uses of the CA-WHOQOL-100 are detailed in Chapter 5 of this manual.

USES OF THE WHOQOL INSTRUMENTS

The Australian WHOQOL instruments have many potential uses; particularly in medical practice, research, audit, policy making and in assessing the effectiveness and relative merits of different treatments. They can also be used to assess variation in QOL across different cultures, to compare subgroups within the same culture, and to measure change across time in response to change in life circumstances. Given its brevity, the WHOQOL-BREF may be more practical than the WHOQOL-100 for use in large epidemiological or research studies, and in clinical settings. The WHOQOL instruments are designed specifically for population use and are not appropriate for use at an individual level (see discussion of the psychometric properties of the WHOQOL-BREF in Chapter 4).

USER AGREEMENT

The Australian WHOQOL-100 instrument has been undergoing development since 1991, the CA-WHOQOL since 1994, and the Australian WHOQOL-BREF since 1995. Each instrument is subject to periodic modifications as additional data become available. Users of the Australian WHOQOL instruments are NOT authorised to make changes to the

WHOQOL instruments. The Melbourne WHOQOL Field Study Centre is responsible for contacting registered users to inform them of any modification to the Australian instruments. Prior to use in any new study, users should consult with the Melbourne WHOQOL Field Study Centre to keep abreast of changes to the instruments. These changes will be reflected in new editions of this manual. Because we are interested in further evidence regarding the reliability and validity of the Australian WHOQOL instruments, we ask WHOQOL users for periodic updates and copies of any publications resulting from use of any of the WHOQOL instruments.

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International publication guidelines are available from the WHOQOL Coordinating Centre at the Department of Mental Health, WHO, Geneva, Switzerland. These guidelines state that WHOQOL users reserve the right to publish information regarding the reliability and validity of the WHOQOL instruments, but are NOT authorised to produce modified versions of the WHOQOL instruments without permission from the WHOQOL Coordinating Centre, Geneva. Any investigator who wishes to publish such a finding is asked to submit a copy of the manuscript to the WHOQOL Coordinating Centre, Geneva for review.

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WHOQOL CENTRES WORLDWIDE

The WHOQOL is a multi-centre international project consisting of a coordinating group, collaborating investigators in each field centre, and a panel of consultants. Dr. J. Orley directs the project and is assisted by Dr. R. Billington. The principal investigators in the original field centres were: Prof. H. Herrman, University of Melbourne, Australia; Dr. Z. Metelco and Dr. S. Szabo, Vuk Vrkovac Institute, Zagreb, Croatia; Dr. N. Quemada, INSERM, Paris, France; Dr. S. Rajkamar, Madras Medical College, India; Dr. S. Saxema, All India Institute of Medical Sciences, New Dehli, India; Dr. M. Amir, Ben-Gurion University, Beer-Sheva, Israel; Dr. M. Tazaki, Science University of Tokyo, Japan; Dr. G. VanHeck, Tilburg University, The Netherlands; Dr. J. Arroyo Sucre, University of Panama, Panama; Dr. M. Kabanov, Bekhterev Psycho Neurological Research Institute, St. Petersburg, Russia; Dr. R. Lucas Carrasco, Barcelona, Spain; Mr. K. Meesapya, Institute of Mental Health, Bangkok, Thailand; Dr. S. Skevington, University of Bath, United Kingdom; Dr. D. Patrick, University of Washington, Seattle, USA; Dr. W. Acuda and Dr. J. Mutambirwa, University of Zimbabwe, Harare, Zimbabwe.

International consultants to the project include: Dr. M. Bullinger, Dr. W. Kuyken, Dr. M. Power and Dr. A. Harper. These consultants, together with Dr. G. VanHeck and Dr. D. Patrick, have participated in the development and analyses of the WHOQOL-100 and WHOQOL-BREF. The complete list of consultants can be obtained from Dr. J. Orley at the WHOQOL Group, Division of Mental Health, World Health Organization, CH-1211 Geneva 27, Switzerland.

More recently the WHOQOL group has added 16 new centres: La Plata, Argentina; Porto Alegre, Brazil; Victoria and Rimouski, Canada; Guangzhou and Boodling City, People's Republic of China; Hong Kong; Mannheim and Leipzig, Germany; Budapest, Hungary; Bologna, Italy; Bergen, Norway; Molndal, Sweden; Rawalpindi, Pakistan; Izmir, Turkey; Hillerod, Denmark; and Tailinn, Estonia. These additional groups are at various stages in the development of centre-specific versions of the WHOQOL.

CHAPTER 2 - THE WHOQOL PROJECT

In 1991, the Division of Mental Health of the World Health Organization (WHO) initiated the World Health Organization Quality of Life (WHOQOL) project. The aim of the WHOQOL project was to develop an internationally-applicable and cross-culturally comparable quality of life (QOL) assessment instrument, the WHOQOL.

The WHOQOL instruments have been developed collaboratively in a number of centres worldwide. The project initially involved 15 centres, namely Australia, Croatia, France, India (two centres), Israel, Japan, The Netherlands, Panama, Russian Federation, Spain, Thailand, United Kingdom, United States of America, and Zimbabwe. As the project grew in scale, new centres became involved. Currently over 30 centres worldwide are involved. Each of the initial 15 national versions of the WHOQOL instrument was developed according to a standardised protocol (WHO 1993a; The WHOQOL Group 1993). As new centres have been and continue to be established, new national versions are being developed according to a standardised Protocol for New Centres (WHO 1994).

This chapter outlines the steps involved in the WHOQOL project, culminating in the development of the WHOQOL-100 and, more recently, the WHOQOL-BREF. While an international perspective is provided, the focus is on the Australian experience. First, the rationale for the development of the WHOQOL instruments is presented. This rationale constitutes a set of principles which guided the developmental process.

RATIONALE FOR DEVELOPING THE WHOQOL INSTRUMENTS

While there has been considerable debate over the past two decades regarding the assessment of QOL, four main principles emerge from the literature on QOL assessment. These four principles have guided the development of the WHOQOL. While many existing QOL measures address *some* of these principles, the WHOQOL was developed as a means of providing an instrument which met *all* of these criteria.

First, the importance of a *comprehensive* assessment of QOL has been recognised increasingly over the last decade (Calman, 1987; Jenkins, Jono, Stanton & Stoup-Benham, 1990; Breslin, 1991; Cello, 1992). Physical assessments alone are inadequate as indicators of QOL (Greenfield & Nelson, 1992), as highlighted by findings of low correlation between self-rated QOL and functional capacities (e.g., Pearlman & Uhlmann, 1988). The WHO definition of health as "a state of complete physical, mental and social wellbeing; not merely the absence of disease and infirmity" (The WHOQOL Group, 1994a, p.43) recognises the breadth of the domains of QOL, and this is reflected in the multidimensional WHOQOL instrument.

Second, the importance of a *subjective* assessment of QOL, applied by patients or clients themselves, has also been acknowledged (Calman, 1987; Breslin, 1991; Cella, 1992; Patrick & Erikson, 1993; Loew & Rapin, 1994; Laman & Lankhorst, 1994). A number of studies have demonstrated that physicians' ratings of the QOL of their patients with chronic illness

are significantly lower than the patients' self-rated QOL (e.g., Pearlman & Uhlmann, 1988; Slevin, Plant, Lynch, Drinkwater & Gregory, 1988). These findings highlight the discrepancy between exogenous and endogenous assessments of QOL. In keeping with this discrepancy, several researchers have discussed the effect of 'adjustable internal standards' on self-perceived ratings of QOL (e.g., Brickman, Coates & Janoff-Bulman, 1978; Cummins, 1995), proposing that our perception of our life alters depending on our expectations, the latter formulated through our experience. This underscores the importance of including subjective ratings of QOL, the approach taken in the WHOQOL instrument.

Third, the *relative importance* of various facets of QOL is also central to the accuracy of the overall assessment of one's QOL (Loew & Rapin, 1994; Laman & Lankhorst, 1994; Hays, Stewart, Sherbourne & Marshall, 1993). The importance of various abilities or disabilities, circumstances or relationships will vary between individuals. Personalised weighting of facets based on self-rated importance scores can account for this and, in a clinical setting, enable targeting of priority areas for treatment (Laman & Lankhorst, 1994). The WHOQOL instrument incorporates importance ratings for each of the QOL facets assessed.

A fourth issue in measuring QOL is the *cultural relevance* of the instrument. QOL instruments need to be culturally-sensitive, comprising items which address culturally-relevant issues and use culturally-relevant language (Sartorius & Kuyken, 1994; Bullinger, Anderson, Cella & Aaronson, 1993; Deyo, 1984). Sartorius and his colleagues emphasise that direct translation of an instrument for use in another cultural setting may be open to serious sources of error because cultural idiosyncrasies and language idiom may not be taken into account (Sartorius & Kuyken, 1994; Kuyken, Orley, Hudelson & Sartorius, 1994). At the same time, with the increasing emphasis on global perspectives in health care, the demand for *cross-cultural comparability* in QOL assessment tools is increasing, introducing the need for development of international QOL measures (Patrick, Wild, Johnson, Wagner & Martin, 1994; The WHOQOL Group, 1994b; 1995).

In the development of the WHOQOL instrument, QOL is defined as:

"an individual's perception of his/her position in life in the context of the culture and value systems in which he/she lives, and in relation to his/her goals, expectations, standards and concerns. It is a broad-ranging concept, incorporating in a complex way the person's physical health, psychological state, level of independence, social relationships, and their relationship to salient features of their environment"

(The WHOQOL Group, 1994a, p.43).

Having been developed within this definition, the WHOQOL-100 instrument is comprehensive and subjective. Given the national centre approach to development described above, it allows for different cultural contexts and self-perceptions of QOL. The inclusion of importance ratings enable personalised or community weightings of facets, further allowing for cultural or individual differences in perceptions of QOL.

In addition, three key features of the developmental process ensured that the WHOQOL is a genuinely international measure which is relevant to a wide range of cultures. First, the

WHOQOL was developed internationally, having initially involved 15 centres and to date involving over 30 centres worldwide. Concurrent development and field testing together with ongoing international collaboration have maximised cross-cultural comparability. Second, the use of focus group discussions in the initial developmental phase ensured the culturally sensitivity and relevance of the language and concepts included in each centrespecific version of the WHOQOL. Third, the use of a tried and tested WHO translation method, involving an iterative process of forward and backward translation and a review process by monolingual and bilingual groups, has ensured conceptual, semantic and technical equivalence in different language versions of the WHOQOL (see Sartorius & Kuyken, 1994). As a result, each WHOQOL instrument is sensitive to the culture in which it is applied, while maintaining cross-cultural comparability.

STAGES IN THE DEVELOPMENT OF THE WHOQOL INSTRUMENTS

The methodology for the development of the WHOQOL instruments is presented fully in two separate papers written on behalf of all participating WHOQOL centres (The WHOQOL Group, 1994a; 1994b). A brief outline of the developmental stages of the WHOQOL instruments is provided here, with a focus on the Australian experience.

Stage 1: Defining Quality of Life

Several previous studies have defined the dimensions of QOL (e.g., Calman, 1987; Jenkins et al., 1990; Breslin, 1991; Cello, 1992). Drawing on this extensive work, five broad domains of QOL, comprising a total of 33 facets, were identified and defined by the WHOQOL group of initial investigators. A facet was defined as a behaviour, state of being, a capacity or potential, or a subjective perception or experience (WHOQOL Group, 1994a; 1994b). The initial WHOQOL domains and facets are shown in Table 2.1.

Table 2.1
Initial WHOQOL domains and facets

Domain	Facet
I Bodily states and functions	1 Pain and discomfort
	2 Vitality and fatigue
	3 Sexual activity
	4 Sleep
	5 Motor functioning
	6 Mobility
	7 Sensory functions
II Psychological functions	8 Cognitive functioning
	9 Happiness and contentment
	10 Depression
	11 Anxiety
	12 Hopefulness and optimism
	13 Self-esteem
	14 Self-efficacy
	15 Body image
III Levels of independence	16 Ability to carry out activities of daily living
	17 Dependence on substances

18 Communication capacity

19 Working capacity

20 Participation in and opportunity for recreation and pastimes

IV Social relationships 21 Isolation/social contact

22 Family support

23 Support from friends/acquaintances 24 Activities as provider/supporter

V Environment 25 Freedom, physical safety and security

26 Quality of home environment 27 Quality of work environment

28 Work satisfaction

29 Opportunities for acquiring new knowledge and skills

30 Financial status

31 Availability/access to health and social care

32 Transport 33 Religion

The processes involved in defining QOL, developing the study protocol, identifying issues relating to QOL based on previous literature and 'expert' discussion, and clustering of these issues into five broad domains and 33 specific facets of QOL are discussed in detail in the above mentioned papers (The WHOQOL Group, 1994a; 1994b).

Stage 2: Focus group work

The benefits of qualitative research prior to instrument development, particularly using focus groups, are widely recognised (e.g., Krueger, 1988; Morgan, 1988; Berg, 1989; Stewart & Shamdasani, 1990). First, the interactive nature of focus group discussions is ideal for stimulating new ideas. In this sense, focus groups are effective for highlighting previously unidentified but relevant aspects of the issue under investigation. Second, focus groups can be used to generate hypotheses which can later be tested more rigorously using additional qualitative and quantitative techniques. Third, the language use and concepts discussed by focus group participants can be incorporated into questionnaire items, thereby ensuring the cultural relevance and sensitivity of a subsequent instrument. Indeed, focus group discussions are an important method for cross-cultural research. Their flexibility and semi-structured nature on the one hand, and their standardised protocols on the other, allow them to yield rich data from widely different populations (WHO, 1993).

In the WHOQOL project, focus group discussions were used to assess the relevance and comprehensiveness of the proposed domains and facets shown in Table 2.1 with members of the local population. Following a standardised protocol (WHO 1992), focus groups were conducted in each of the initial 15 participating centres. These centres were located in Australia, Croatia, France, India (two centres), Israel, Japan, The Netherlands, Panama, Russian Federation, Spain, Thailand, United Kingdom, United States of America and Zimbabwe. Using the same procedures in each centre, the meaning, relevance and relative importance of each of the 33 specified facets was discussed, and previously omitted aspects of QOL were identified.

To ensure that the focus groups represented a wide range of views, three different populations were sampled: patients, 'well' lay people, and health professionals. In each centre, two separate groups were convened for each population, with a total of six focus groups being conducted. In Melbourne, the six focus groups involved a total of 15 patients, 14 'well' lay people, and 19 health professionals.

Findings from the focus group discussions were utilised in two ways. First, at the international level, the list of WHOQOL domains and facets was modified, collapsed and extended in the light of focus group findings from each centre, taking into account the perceived relevance and relative importance of the initial domains and facets, together with newly identified aspects of QOL. Second, at the national level, proposed items for the WHOQOL instrument were generated with reference to the content and language of the focus group discussions. This ensured the cultural relevance and sensitivity of the content and language of items in each of the centre-specific versions of the WHOQOL. The findings of the focus group research conducted in eight of the initial centres were incorporated into a single report by investigators at WHO headquarters in Geneva (WHO, 1993). The findings specific to the Australian focus groups are also presented in a separate report (Murphy, Schofield & Herrman, 1999).

At the international level, the findings of the focus groups provided considerable validation of the domains and facets proposed for the WHOQOL. Across the eight centres, the mean importance rating for each facet was above the midpoint, indicating that all facets were at least 'important' and, in many cases, 'very' or 'most' important.

Nonetheless, a considerable number of changes were made to the initial proposed facet structure for the WHOQOL on the basis of the international focus group work. Several facet definitions were broadened or altered so that two or more of the initial facets were subsumed within a single facet (eg. 'positive affect' subsumed 'happiness & contentment' and 'hopefulness & optimism'). Some new facets, identified by focus group participants to be important to their QOL, were added to the facet list (eg. 'intimacy/loving relationships'). In addition, 'spirituality, religion, personal beliefs' was split off as a broad domain of QOL rather than a facet of the environment domain. As emphasised in WHO (1993) report which detailed all changes to the facet structure, many of the suggested changes were proposed in several of the centres, thus providing validation of the revised facet structure. Table 2.2 shows the WHOQOL facet structure following the focus group work.

Table 2.2 WHOQOL domains and facets following focus group work

Domain	Facet
I Physical health	1 General health
•	2 Pain and discomfort
	3 Energy and fatigue
	4 Sexual activity
	5 Sleep and rest
II Psychological health	6 Positive affect
-	7 Sensory functions
	8 Thinking, learning, memory and concentration

9 Self-esteem

10 Body image and appearance

11 Negative affect

III Level of independence

12 Mobility

13 Activities of daily living

14 Dependence on substances

• Medicinal substances

• Non-medicinal substances

15 Communication capacity

16 Work capacity

IV Social relationships 17 Intimacy/loving relationships

18 Practical social support

19 Activities as provider/supporter

V Environment 20. Physical safety and security

21 Home environment 22 Work satisfaction 23 Financial resources

24 Health and social care: accessibility and quality

25 Opportunities for acquiring new information and skills

26 Participation in and opportunities for recreation/leisure activities

27 Transport

VI Spiritual domain 28 Spirituality/religion/personal beliefs

Stage 3: Item generation task

After completion of the focus group work, an item-writing panel was assembled in each field centre. In Melbourne, this panel comprised the Melbourne investigators, the focus group moderator and a lay person. Using the focus group transcripts, the panel generated six items for each facet, at each of two levels of questioning: "perceived objective" and "self-report subjective". As far as possible, the language of the focus group participants was used in framing the items. Several other criteria for items were also applied. Again the procedure used was standardised across centres so as to facilitate conceptual and semantic equivalence between cultural settings and minimise translation-related difficulties at a very early stage in the development of the instrument.

¹ 'Perceived objective' items refer to a person's global evaluations of behaviours, states or capacities, and inform about the individual's assessment of their physical and psychological health, level of independence, social relationships and environment conditions. 'Self-report subjective' items assess a person's satisfaction/dissatisfaction with their behaviour, state or capacity. ie. these probe to what extent the person feels that their needs and wants are being met, and how much they feel that a problem or difficulty prevents them from doing what they want or need to do.

² Items were designed to: (a) be based as far as possible on the suggestions of focus group participants; (b) give rise to answers that are illuminating about respondents' quality of life as defined in the project; (c) be amenable to a rating scale; (d) reflect the meaning conveyed in the facet definition; (e) in combination with other questions for a given facet, cover the key aspects of that facet as outlined in the facet definition; (f) avoid any explicit reference point in terms of time or comparison points (eg. the ideal, or before I was ill); (g) be applicable to patients with a range of impairment; (h) be phrased as questions rather than statements; (i) be shorter rather than longer; (j) avoid double negatives; and (k) avoid any ambiguities in terms of wording or phrasing.

Items from each centre were then pooled to make up a "global question pool". This pool was reduced following identification of: (a) duplicate items, (b) semantically equivalent items, and (c) items which did not meet the criteria for WHOQOL items. The final pool comprised around 1000 items.

These items, presented in conceptual clusters within each facet, were then distributed to each field centre. The principal investigator and centre coordinators in each field centre rank ordered items within each facet according to "how much it tells you about a respondent's quality of life in your culture". On the basis of the combined rankings from all centres, 236 items were selected for the *WHOQOL pilot instrument*. These items tapped the "perceived objective" and "self-report subjective" levels of QOL. The conceptual clusters were useful in ensuring that the questions selected for the pilot WHOQOL addressed all the important aspects of each facet. An additional 41 "importance items" were also included in the pilot instrument, enabling assessment of the relative importance of each facet.

Stage 4: Australian response scale derivation task

The WHOQOL instruments contain five different 5-point response scales concerned with intensity (not at all – extremely), capacity (not at all – completely), frequency (never – always), and evaluation (very satisfied – very dissatisfied; very good – very poor). While end points such as "never" and "always" are relatively universal and easily translated, the shades of meaning between end-points (eg. "rarely", "sometimes", "almost always") are more ambiguous, difficult to translate, and subject to cultural variation in interpretation (Sartorius & Kuyken, 1994). Thus, rather than directly translate English response scales, culturally-relevant response scales were developed in each field centre. While the end-points (points 1 and 5) in rating scales are consistent across field centres, the anchor points *along* the scale (points 2,3 and 4) are centre-specific.

A standardised method was employed for generating culturally-relevant response scales. In each centre, a list of at least 15 *possible* anchor point descriptors was generated for each question type (intensity, capacity, frequency and evaluation). Using 100mm visual analogue scales (VAS) marked with the standard end-points for each question type, a sample of lay respondents (n=20 in each centre) indicated where on the scale they felt each of the possible anchor points was situated in relation to the two end-points. A separate VAS was used for each possible anchor point. The three intermediate descriptors were then chosen on the basis of their mean position, with the anchor points in the ranges of 20-30mm, 45-55mm and 70-80mm being selected. If several descriptors fell within a given range, the descriptor with the smallest standard deviation was chosen. A bilingual review process was used to check on the comparability of the derived descriptors between centres.

Stage 5: Australian pilot testing of the 236-item version

The 236-item pilot WHOQOL instrument was standardised across field centres with regard to formatting, instructions, headers and question order. All questions asked about "the last two weeks". On the whole, questions were grouped according to response scales, thus facilitating ease of completion. The 41 "importance" questions, asking respondents to indicate the importance of each facet to their quality of life, were included as a set at the end

of the instrument. Following a standardised protocol, a field test of the pilot instrument was undertaken in each of the WHOQOL field study centres, with a target sample of 300 respondents (both patients and well people). Centre-specific response scales were applied to the instrument piloted in each centre. The following is an outline of the Australian field-trial of the 236-item WHOQOL instrument.

Sample and recruitment

In Melbourne, a sample of 247 'patients' and 53 'well persons' completed the pilot WHOQOL instrument. The sample of patients comprised 169 hospital outpatients, 18 hospital inpatients, and 60 general practice (GP) patients. Outpatients were recruited from five outpatient clinics at St. Vincent's Hospital, namely the liver, hand, plastic surgery, vascular and gastroenterology clinics. Outpatients were approached by the researcher and asked to complete the questionnaire while waiting for their appointment. Completed questionnaires were collected immediately. Respondents unable to complete the questionnaire during the waiting time were given a reply-paid envelope and asked to complete and return the questionnaire during the following week. All patients attending the clinic on that day were approached, except those deemed by the Outpatients Charge Nurse to be unfit to complete the questionnaire. Because the questionnaire was in English, patients who did not speak English were necessarily excluded. Inpatients were recruited from the physiotherapy and gastroenterology departments of St. Vincent's Hospital. With direction from the Departmental Charge Nurse, patients were approached by the researcher and asked to complete the questionnaire when convenient. The Charge Nurse notified the researcher once all questionnaires had been completed and collected. GP Patients were recruited from two GP surgeries in Melbourne. Again they were approached by the researcher and asked to complete the questionnaire while waiting for their appointment. Completed questionnaires were either collected immediately or, more often, returned in a reply-paid envelope during the following week. Non-English speaking patients were again excluded. The sample of well persons comprised relatives or informal carers accompanying patients, recruited through either outpatient or general practice waiting rooms. Again completed questionnaires were returned either immediately or by mail during the following week. Importantly, while not necessarily comprised of 'well' persons, this group of non-patients provides a valuable comparison for the two patient samples.

Respondents included both men and women, and covered a wide range of ages and illness groups. Most (61%) were female. The mean age was 41.3 years, with a standard deviation of 16.6 years. In total, 69.5% were classified as "sick".

Stage 6: Item reduction based on internationally-pooled pilot data

Pilot data from each of the field centres was pooled and analysed centreally by WHO in Geneva. The aim of the analysis was to reduce the 236 item pool down to 100 items which demonstrated relevance across the wide variety of centres. The analysis process included examination of item distributions, item-facet correlations, and the overall factorial structure, undertaken for both individual centres and for the full data set. These procedures enabled identification of items with frequency problems, reliability problems, and/or non-predicted or multiple factor loadings (whereby the item correlates significantly with a facet other than or as well as the predicted facet), taking into account both national and international trends.

Comparisons between sick and well populations enabled identification of non-discriminating items. Correlations with each of the five general QOL items provided additional data on the construct validity of items. Because most correlations between 'perceived objective' and 'self-report subjective' items within facets were found to be at r>0.8, this distinction was dropped for subsequent versions of the WHOQOL. Five facets which comprised only problematic items were also excluded.

Following the analyses described above, 24 specific facets and one facet relating to overall QOL and general health remained (25 in total). In order to reduce the instrument length yet retain adequate reliability, it was decided to retain four items per facet (totaling 100 items). The selection of items took into account the extent and rank order of an item's facet loading on a principal components factor analysis, the degree of conceptual overlap between potential items, and the extent of problems indicated by the earlier analyses. The criteria applied in the selection and rejection of items, the rationale for these criteria, and the process of rejecting items and facets and thereby arriving at the final 100 items are discussed in more detail elsewhere (The WHOQOL Group, 1998a).

The resulting 100-item version of the instrument is known as the WHOQOL-100. While each centre-specific version of the WHOQOL-100 contains the same items for each facet, item wording differs in each version to take account of cultural idiosyncrasies and sensitivities. In addition, each version carries centre-specific response scales. Some centres also include a number of additional centre-specific items (not comparable across centres), although this is not the case in the Australian version. The Australian WHOQOL-100 is discussed in detail in the following chapter. The shorter Australian WHOQOL-BREF, which comprises a subset of 26 items, is discussed in detail in Chapter 5.

CHAPTER 3 - THE AUSTRALIAN WHOQOL-100

DESCRIPTION OF THE AUSTRALIAN WHOQOL-100

The *Australian WHOQOL-100* is a 100-item self-administered instrument consisting of six domains: Physical, Psychological, Independence, Social relationships, Environment, and Spiritual. These domains contain 24 facets of four items each, for a total of 96 items. One additional facet (4 items) pertains to global QOL and general health. The facets and domains of the WHOQOL-100 are presented in Table 3.1. A copy of the Australian WHOQOL-100 is presented in Appendix I. Details of the development and general psychometric properties of the international WHOQOL-100 are presented in The WHOQOL Group (1998a).

Table 3.1 Domains and facets of the WHOQOL-100

Domain	Facet
I Physical health	1 Pain and discomfort
	2 Energy and fatigue
	3 Sleep and rest
II Psychological health	4 Positive affect
	5 Thinking, learning, memory and concentration
	6 Self-esteem
	7 Body image and appearance
	8 Negative affect
III Level of independence	9 Mobility
	10 Activities of daily living
	11 Dependence on medication or treatments
	12 Working capacity
IV Social relationships	13 Personal relationships
	14 Social support
	15 Sexual activity
V Environment	16 Physical safety and security
	17 Home environment
	18 Financial resources
	19 Health and social care: accessibility and quality
	20 Opportunities for acquiring new information and skills
	21 Participation in and opportunities for recreation/leisure activities
	22 Physical environment (pollution, noise, traffic, climate)
	23 Transportation
VI Spiritual domain	24 Spirituality/religion/personal beliefs
Additional	25 Overall Quality of life and general health

A 5-point response scale is used to rate the intensity, frequency, capacity or evaluation of the selected areas of QOL. The relevant Australian-derived response scales are used in the Australian WHOQOL-100. The WHOQOL-100 affords separate facet and domain scores, including a score for the facet pertaining to global QOL and general health. There is currently no procedure for combining the domain scores into a QOL index. A high score on

any of the WHOQOL-100 domains corresponds to a favorable QOL. Scoring procedures are detailed later in this chapter.

THE IMPORTANCE ITEMS

There are 32 additional items which ask respondents to indicate the importance to their overall QOL of each of the facets of QOL addressed in the WHOQOL-100. Some facets have more than one corresponding importance item. The importance items use a 5-point response scale (1=not important to 5=extremely important). The Australian importance items are presented in Appendix II.

The importance items were designed to be used to provide personalised weightings of facets in assessments of QOL. They are separate from and can be administered alongside the WHOQOL-100 items. However, administration of the importance items is not essential. While the potential remains, a standardized method for weighting facets on the basis of importance ratings has not yet been established. In studies where the WHOQOL is one of several inventories, or in cases where brevity is desired, users may prefer to administer the WHOQOL-100 without the importance items. The WHOQOL Group will continue to consider the issue of facet weighting using responses to the importance items, and implications for scoring will be included in future editions of this manual.

PSYCHOMETRIC PROPERTIES OF THE WHOQOL-100: INTERNATIONAL DATA

The psychometric properties of the WHOQOL-100 were initially investigated using relevant data extracted from the international pilot testing of the 236-item version of the WHOQOL. This data was based on a sample of 4802 respondents from one of 15 field study centres worldwide, therefore representing global data. Respondents included both men and women, and covered a wide range of ages and illness groups. Most (53.8%) were female. The mean age was 43.4 years, with a standard deviation of 16 years. In total, 81% were classified as "sick".

On the basis of these global data, all facets of the WHOQOL-100 demonstrated good *internal consistency*, with Cronbach's alphas ranging from 0.65 (for physical environment) to 0.93 (for working capacity). In terms of *discriminant validity*, all but one facet (physical environment) showed significant differences in mean scores for 'well' and 'sick' samples. These initial analyses, which provide some indication that the WHOQOL-100 has acceptable psychometric properties for all the 15 centres studied, are discussed in detail elsewhere (The WHOQOL Group, 1998a).

INITIAL VALUES BASED ON FIELD TESTING OF THE AUSTRALIAN WHOQOL-100

As discussed in Chapter 2, data from the international pilot testing of the 236-item version of the WHOQOL were analysed centrally in Geneva. By extracting the relevant 100 items from this 236-item data set, exploration of the mean facet and domain scores for the WHOQOL-100 items was possible. This analysis was undertaken separately for each of the 15 participating centres, and findings are presented in full in The WHOQOL Group (1998a). Mean (and standard deviation) facet and domain scores for the Melbourne sample (n=300) are presented in Table 3.2. While the sample was not representative, these initial values are useful as a guide to means and standard deviations for the facets and domains of the Australian WHOQOL-100.

Table 3.2 *Mean scores and standard deviations for facets and domains of the Australian WHOQOL-100*

	Mean	SD
I Pain and discomfort	9.4	3.2
2 Energy and fatigue	13.5	3.2
3 Sleep and rest	14.2	3.7
4 Positive affect	14.1	2.7
5 Thinking, learning, memory & concentration	14.9	2.6
6 Self-esteem	14.7	2.8
7 Body image and appearance	15.2	3.2
8 Negative affect	9.3	3.6
9 Mobility	16.5	3.5
10 Activities of daily living	16.4	3.0
11 Dependence on medication or treatment	7.9	4.4
12 Working capacity	15.9	4.0
13 Personal relationships	15.4	2.8
14 Social support	15.2	3.1
15 Sexual activity	13.8	4.1
16 Physical safety & security	15.1	2.7
17 Home environment	15.9	2.7
18 Financial resources	13.6	3.8
19 Health and social care: access & quality	15.4	2.4
20 Opportunity for acquiring info & skills	15.1	2.7
21 Participation & opportunity for rec/leisure	14.2	2.8
22 Physical environment	14.3	2.7
23 Transportation	16.7	3.0
24 Spirituality/religion/personal beliefs	14.2	3.4
25 Overall Quality of life/general health	14.7	3.1
DOMAIN 1	14.1	2.7
DOMAIN 2	14.7	2.3
DOMAIN 3	16.2	3.0
DOMAIN 4	14.8	2.7
DOMAIN 5	15.0	1.9
DOMAIN 6	14.2	3.4

Note. N=300 (n=247 patients; n=53 'well' persons) from the Melbourne pilot testing of the 236-item version of the Australian-WHOQOL. Only items retained for the WHOQOL-100 are

included. Each of the 25 facets comprises four items scored on a 5-point scale. The possible score range for facets and domains is 4-20. Higher scores indicate better QOL. Data presented here is extracted from data presented in The WHOQOL Group (1998a; p.1579).

FIELD TESTING OF THE AUSTRALIAN WHOQOL-100

The Australian WHOQOL-100 is currently being used in a small number of studies in Australia. At the time of writing, these studies are in the preliminary stages. As results become available, further information regarding the psychometric properties of the Australian WHOQOL-100 will be incorporated into updated editions of this manual.

ADMINISTRATION GUIDELINES

The WHOQOL-100 was designed for self-administration, but can be interviewer-administered if necessary. The WHOQOL co-ordinating group suggests that self-administration time for 'well' people who are literate in the relevant language is between 20-30 minutes, while interviewer-administration requires 40-90 minutes.

Self-administration

Participants should be instructed to complete the WHOQOL-100 in a quiet place, free from distractions and influences from other people. Items should always be administered in the order in which they appear in the WHOQOL-100, and the response scales should not be altered. The cover page, which gives brief instructions and an example of how to respond to the questions, should always be included. Questions regarding respondents' demographic and health details are included on the final page of the WHOQOL-100 and should be administered with the WHOQOL, unless they are incorporated into a separate demographic questionnaire.

Inclusion of the 32 'importance items' is optional: these items were designed to be used for 'weighting' responses to the 100 items, but a standardized method for item-weighting has not yet been devised. For the sake of brevity and to minimise response burden, the importance items may be omitted if preferred. This manual will be updated with details regarding administration of the importance items in due course.

Interviewer administration

Before beginning the questionnaire, the interviewer should read out the instructions provided on the front page of the WHOQOL-100, including the example item and responses. The interviewer can also give an estimation of the time the interview will take.

During the interview, the respondent should be made to feel comfortable enough to ask the interviewer to slow down, repeat a question, or speed up. The response options can be repeated with each item. For long lists of items, the lead-in can be repeated periodically so that the respondent is reminded of the meaning of the response options. By way of encouragement, the interviewer can inform the respondent when they are halfway through the questionnaire. If appropriate, the respondent should have a copy of the questionnaire to follow along, regardless of their ability to read.

Interviewers should be trained, as good interviewing skills will minimise bias. Interviewers should never express their own opinions and should avoid giving cues in their language, vocal inflection, posture, and facial expressions. Even apparently encouraging expressions such as smiling and nodding can introduce bias into the responses. Interviewers should not explain the items: misunderstood items should simply be repeated, and respondents should be encouraged to interpret these in their own way. Any comments made by the interviewer should be recorded on the questionnaire, to enable identification of potential bias.

SCORING

The WHOQOL-100 produces a QOL profile. It is possible to derive:

- (a) 24 individual facet scores;
- (b) six domain scores; and
- (c) general QOL and health perceptions scores (based on the four questions pertaining to global QOL and general health).

The 24 facet scores denote the individual's evaluation of his/her functioning in the particular area of life addressed by that facet. The six domain scores denote an individual's perception of QOL in each particular QOL domain. The WHOQOL-100 is scored through straightforward summative scaling, with item score-reversal where necessary. Methods for obtaining facet and domain scores are presented below. A computer diskette containing the necessary algorithms for computing facet and domain scores, based on SPSS, is supplied together with this manual.

Facet scores

Facet scores are obtained by summing scores for the four constituent items from that facet.³ Several facets contain items which need to be reverse-scored before facet scores are calculated, using the formula "x(rev)=6-x".

The formulae for calculating facet scores are as follows:

```
Overall QOL and General Health = Q53 + Q54 + Q55 + Q81 Facet 1 (F1) = Q1 + Q2 + Q25 + Q86 Facet 2 (F2) = (6-Q26) + (6-Q27) + Q40 + Q56 Facet 3 (F3) = (6-Q3) + (6-Q4) + Q57 + Q83 Facet 4 (F4) = Q5 + Q6 + Q28 + Q87 Facet 5 (F5) = Q29 + Q58 + Q59 + Q84 Facet 6 (F6) = Q7 + Q8 + Q60 + Q61
```

consistency in response scales rather than on consecutive order in terms of original item numbers.

³ In earlier WHOQOL versions, items were numbered to indicate the facet to which they belong: eg. Facet 1

comprised Items F1.1 to F1.4; Facet 7 comprised Items F7.1 to F7.4. Correspondences between the current item numbers and original item numbers are as follows: Q1=F1.2, Q2=F1.4, Q3=F3.2, Q4=F3.4, Q5=F4.1, Q6=F4.4, Q7=F6.1, Q8=F6.2, Q9=F7.3, Q10=F8.3, Q11=F8.4, Q12=F10.2, Q13=F10.4, Q14=F11.2, Q15=F11.3, Q16=F11.4, Q17=F17.4, Q18=F16.3, Q19=F18.2, Q20=F18.4, Q21=F21.3, Q22=F22.2, Q23=F23.2, Q24=F23.4, Q25=F1.3, Q26=F2.2, Q27=F2.4, Q28=F4.3, Q29=F5.3, Q30=F7.2, Q31=F8.2, Q32=F13.1, Q33=F15.2, Q34=F15.4, Q35=F16.1, Q36=F16.2, Q37=F17.1, Q38=F19.1, Q39=F22.1, Q40=F2.1, Q41=F7.1, Q42=F10.1, Q43=F11.1, Q44=F14.1, Q45=F14.2, Q46=F17.2, Q47=F18.1, Q48=F20.1, Q49=F20.2, Q50=F21.1, Q51=F21.2, Q52=F23.1, Q53=G2, Q54=G3, Q55=G4, Q56=F2.3, Q57=F3.3, Q58=F5.2, Q59=F5.4, Q60=F6.3, Q61=F6.4, Q62=F7.4, Q63=F10.3, Q64=F13.3, Q65=F15.3, Q66=F14.3, Q67=F14.4, Q68=F13.4, Q69=F16.4, Q70=F17.3, Q71=F18.3, Q72=F19.3, Q73=F19.4, Q74=F20.3, Q75=F20.4, Q76=F21.4, Q77=F22.3, Q78=F22.4, Q79=F23.3, Q80=F13.2, Q81=G1, Q82=F15.1, Q83=F3.1, Q84=F5.1, Q85=F19.2, Q86=F1.1, Q87=F4.2, Q88=F8.1, Q89=F12.1, Q90=F12.2, Q91=F12.4, Q92=F12.3, Q93=F9.1, Q94=F9.3, Q95=F9.4, Q96=F9.2, Q97=F24.1, Q98=F24.2, Q99=F24.3, Q100=F24.4. For ease of completion, the ordering of items in the WHOQL-100 is based on

```
Facet 7 (F7) = (6-Q9) + (6-Q30) + Q41 + Q62
Facet 8 (F8) = Q10 + Q11 + Q31 + Q88
Facet 9 (F9) = Q93 + (6-Q94) + (6-Q95) + Q96
Facet 10 (F10) = (6-Q12) + (6-Q13) + Q42 + Q63
Facet 11 (F11) = Q14 + Q15 + Q16 + Q43
Facet 12 (F12) = O89 + O90 + O91 + O92
Facet 13 (F13) = (6-Q32) + Q64 + Q68 + Q80
Facet 14 (F14) = Q44 + Q45 + Q66 + Q67
Facet 15 (F15) = Q33 + (6-Q34) + Q65 + Q82
Facet 16 (F16) = (6-Q18) + Q35 + Q36 + Q69
Facet 17 (F17) = Q17 + Q37 + Q46 + Q70
Facet 18 (F18) = (6-Q19) + (6-Q20) + Q47 + Q71
Facet 19 (F19) = Q38 + Q72 + Q73 + Q85
Facet 20 (F20) = Q48 + Q49 + Q74 + Q75
Facet 21 (F21) = Q21 + Q50 + Q51 + Q76
Facet 22 (F22) = (6-Q22) + Q39 + Q77 + Q78
Facet 23 (F23) = (6-Q23) + (6-Q24) + Q52 + Q79
Facet 24 (F24) = Q97 + Q98 + Q99 + Q100
```

Table 3.3 shows the direction of scaling for each facet and constituent reverse-scored items. For the 21 positively-framed facets, scores are scaled in a positive direction (ie. higher scores indicate higher QOL). For the three negatively-framed facets, scores are scaled in a negative direction (and will be reverse-scored in calculating domain scores). Because each facet comprises four items, all facet scores range from 4-20, with a possible score range of 16.

Table 3.3 Direction of scaling and reverse-scored items for each facet of the WHOQOL-100

Facet		Direction of scaling	Reverse-scored items
Overa	all QOL and General health	+	none
F1	Pain and discomfort	-	none
F2	Energy and fatigue	+	Q26 and Q27
F3	Sleep and rest	+	Q3 and Q4
F4	Positive feelings	+	none
F5	Thinking, learning, memory & concentration	+	none
F6	Self-esteem	+	none
F7	Body image and appearance	+	Q9 and Q30
F8	Negative feelings	-	none
F9	Mobility	+	Q94 and Q95
F10	Activities of daily living	+	Q12 and Q13
F11	Dependence on medication or treatment	-	none
F12	Working capacity	+	none
F13	Personal relationships	+	Q32
F14	Social support	+	none
F15	Sexual activity	+	Q34
F16	Physical safety & security	+	Q18
F17	Home environment	+	none
F18	Financial resources	+	Q19 and Q20
F19	Health and social care:availability & access	+	none

F20	Opportunities for acquiring new info & skills	+	none
F21	Participation in & opportunity for recreation	+	none
F22	Physical environment: pollution/noise etc	+	Q22
F23	Transportation	+	Q23 and Q24
F24	Spirituality/religion/personal beliefs	+	none

Transformation of facet scores to 0-100 Scale (optional)

While not commonly necessary, facet scores can be transformed to a 0-100 scale, for ease of comparison with other data sets. This transformation converts the lowest possible score to zero and the highest possible score to 100. Scores between these values represent the percentage of the total possible score achieved.

Raw scores are transformed using the following formula:

Domain scores

Domain scores are obtained by summing scores on the relevant facets (F1 to F24). Because the six domains contain different numbers of facets, the summative score needs to be divided by the number of facets contained in that domain in order to achieve comparability between domains. All domain scores are scaled in a positive direction (ie. higher scores denote higher QOL). As such, the three negatively-framed facets need to be reverse-scored in calculating domain scores, as shown in the formulae. Like the facet scores, all domain scores range from 4-20.

The formulae for calculating domain scores from facet scores are as follows:

Physical domain =
$$(\underline{24\text{-F1 score}}) + \underline{F2 score} + \underline{F3 score}$$

Psychological domain = F4 score + F5 score + F6 score + F7 score + (24-F8 score)

5

Level of independence domain = $\frac{F9 \ score + F10 \ score + (24-F11 \ score) + F12 \ score}{4}$

Social relationships domain = $\frac{F13 \ score + F14 \ score + F15 \ score}{3}$

Spiritual domain = F24 score

CHAPTER 4 - THE AUSTRALIAN WHOQOL-BREF

DESCRIPTION OF THE AUSTRALIAN WHOQOL-BREF

The Australian WHOQOL-BREF contains 26 items. The instrument comprises one item from each of the 24 facets contained in the WHOQOL-100, plus two items from the overall quality of life and general health facet. The WHOQOL-BREF was developed from the larger WHOQOL-100 data sets available from all WHOQOL centres to the Geneva coordinating centre. This shorter version may be preferred by many researchers, particularly where the research involves repeated measures designs, large epidemiological surveys, clinical trials, and where respondents/patients have difficulty completing the longer version. Like the WHOQOL-100, all items in the WHOQOL-BREF are rated on a 5-point scale. Four types of scales are used to assess intensity, capacity, frequency and evaluation. The Australian-derived response scales are used in the Australian WHOQOL-BREF. A copy of the Australian WHOQOL-BREF is presented in Appendix III. Details of the development and general psychometric properties of the international WHOQOL-BREF are presented in The WHOQOL Group (1998b).

While the initial conceptual framework for the WHOQOL-100 six domains, subsequent data analysis yielded a four-factor model (The WHOQOL Group, 1998a). Using the international pilot data, Principal Components Analysis with Varimax Rotation was carried out on a random split half of the sample (n=2056). The analysis yielded four factors with eigenvalues greater than one, explaining 58% of the variance. The first factor included facets from the physical and independence domains, reflecting a physical capacity domain. The second factor comprised all facets from the environment domain. The third factor comprised three psychological facets and the spirituality facet. The fourth factor encompassed all social relationship facets and the body image facet. The facet relating to overall QOL of life cross-loaded on all factors. The four factor model was shown to be superior to the six factor model in terms of 'degree of fit', for both ill and well populations (The WHOQOL Group, 1998a; 1998b). On the basis of these analyses, these four domains were considered most appropriate for the WHOQOL-BREF. Table 4.1 shows how the facets from the WHOQOL-100 have been incorporated into the four domains of the WHOQOL-BREF, namely the physical, psychological, social relationships, and environment domains.

FIELD TESTING OF THE AUSTRALIAN WHOQOL-BREF

Field-testing of the WHOQOL-BREF is underway in Australia, with several studies currently being conducted or completed. Two of these studies are outlined briefly below, followed by findings related to the psychometric properties of the WHOQOL-BREF.

The Victorian Validation Study

The Victorian Validation Study (VVS) was conducted by the Centre for Health Program Evaluation, Melbourne. The study provides WHOQOL-BREF data based on random sampling of the population, and is the only Australian study to do so. A preliminary report of the study and an overview of the findings is provided in Hawthorne, Richardson et al. (2000).

Table 4.1 Domains and facets of the WHOQOL-BREF (one item for each facet)

Domain	Facet
Overall QOL and general health	a Overall QOL
	b Satisfaction with health
I Physical health	1 Pain and discomfort
•	2 Dependence on medical treatment
	3 Energy and fatigue
	4 Mobility
	5 Sleep and rest
	6 Activities of daily living
	7 Work capacity
II Psychological health	8 Positive affect
	9 Spirituality
	10 Thinking, learning, memory and concentration
	11 Body image and appearance
	12 Self-esteem
	13 Negative affect
IV Social relationships	14 Personal relationships
	15 Sexual activity
	16 Social support
V Environment	17 Physical safety and security
	18 Physical environment (pollution, noise, traffic, climate)
	19 Financial resources
	20 Opportunities for acquiring new information and skills
	21 Participation in and opportunities for recreation/leisure activities
	22 Home environment
	23 Health and social care: accessibility and quality
	24 Transportation

In the VVS, six health-related quality of life (HRQoL) instruments were administered to a stratified sample of Victorian residents, selected to cover a very broad range of health conditions from full health to terminal illness. The strata were: (a) randomly selected community members weighted by socio-economic status to achieve representativeness of the Australian population (n=396); (b) outpatients attending two of Melbourne's largest public hospitals (n=334); and (c) inpatients from three Melbourne hospitals (n=266). In

recruiting outpatients, random sampling within selected timeframes was used. In recruiting inpatients, purposive sampling within wards based on severity of condition was used. The six instruments included two generic health status instruments - the WHOQOL-BREF and the Short Form 36 (SF-36) - and four utility instruments - the Assessment of Quality of Life (AqoL), the EQ5D (formerly the EuroQoL), the Health Utilities Index – Mark 3 (HUI3) and the 15D. For the generic instruments, item responses were recoded or weighted and then summed to form domain or dimension scores. For the utility instruments, item responses were weighted and combined to produce an index.

The Longitudinal Investigation of Depression Outcomes Study

The Longitudinal Investigation of Depression Outcomes (LIDO) Study is a multi-centre, cross-national observational study of depressed patients, with a comparison sample of non-depressed controls. It's aim is to explore the relationship between major depressive disorders in primary care patients and their quality of life and resource use. The study is being conducted concurrently in six WHOQOL field study centres, namely Australia, Brazil, Israel, Russian Federation, Spain and United States of America. While the overall study aims to explore cross-cultural differences in treatment patterns and resource use amongst depressed patients, the Australian-based data provided an opportunity to assess the psychometric properties of the Australian WHOQOL-BREF.

In Australia, in accordance with the LIDO protocol, WHOQOL-BREF data was collected for a 'depressed' sample (n=437 with attrition) on four separate occasions, and for a 'non-depressed' sample (n=115) on two separate occasions. Strict inclusion criteria were applied, based on both the Centres for Epidemiologic Studies- Depression (CES-D), administered at the initial screening interview, and the Composite International Diagnostic Interview (CIDI), administered at baseline assessment. A sample of individuals with CES-D scores below 16 were included in the 'non-depressed' sample. Those with CES-D scores of 16 or above, not in treatment for depression and available for assessment over the following 12 months, were assessed at baseline, with patients meeting the criteria for current depression based on the CIDI 2.1 screening criteria and willing to participate further being included in the 'depressed' sample. In addition to the WHOQOL-BREF, one other QOL instruments – the Short Form 12 (SF-12) - was administered to the 'depressed' sample. Treatment for depression was also recorded.

PSYCHOMETRIC PROPERTIES OF THE AUSTRALIAN WHOQOL-BREF

The healthy sample from the VVS provides population norms for the WHOQOL-BREF, information regarding the internal structure of the instrument (factor structure and internal

consistency of domains), plus indications of its construct validity and discriminant validity. The Australian LIDO data provides indications of the internal consistency, test-retest reliability, construct validity, discriminant validity, and sensitivity to change of the WHOQOL-BREF. Drawing on both the VVS data and the LIDO data, this section presents findings relating to the psychometric properties of the Australian WHOQL-BREF. In all cases, results are reported for each of the four BREF domains. In addition, results relevant to items 1 and 2 are reported where applicable. Both these items are intended as indicators of 'overall QOL', with item 1 referring to 'general QOL' and item 2 referring to 'satisfaction with health'.

Australian population norms

Means, standard deviations (SD) and score ranges for the four domains and the two 'overall QOL' items of the Australian WHOQOL-BREF from the VVS are presented in Table 4.2.

As shown in Table 4.2, mean scores for the four domains ranged from 72 (social) to 80(physical). Mean scores for the two overall QOL items were 4.3 for item 1 (QOL) and 3.6 for item 2 (health). Being based on a stratified community sample, these VVS data provide an accurate indication of population norms for the WHOQOL-BREF.

Table 4.2 Population norms for the Australian WHOQOL-BREF domains and global items

Domain or item	N	Mean	SD	Score range
Domains				
Physical	396	80.0	17.1	3.6-100.0
Psychological	396	72.6	14.2	20.8-100.0
Social relationships	396	72.2	18.5	8.3-100.0
Environment	396	74.8	13.7	25.0-100.0
Items				
Item 1: 'QOL'	396	4.3	0.8	1-5
Item 2: 'health'	396	3.6	0.9	1-5

Note. Domain score range is 0-100; item score range is 1-5. Higher scores indicate better QOL. SD=standard deviation.

When domain mean scores were compared by rank, there were significant differences: Physical health was ranked higher than the environment domain, which was ranked higher than both the social relationships and psychological domains (Kendall coefficient of concordance, W=0.06, p<.01). Interestingly, despite its low ranking, the lowest fifth of the potential range of the psychological domain was not used at all. The environment domain also had a truncated lower range.

 $^{^4}$ Full details of the VVS analyses and findings are presented in Hawthorne, Richardson, Day & McNeil (2000).

Factor structure

In order to examine the factor structure of the WHOQOL-BREF, Principal Component Analysis with Varimax Rotation (EFA) was performed on the VVS data. Results are shown in Table 4.3.

Table 4.3 Factor structure of the Australian WHOQOL-BREF

	No. of	Principal component analysis				
	items	Loading range of items	Eigenvalue	% variance explained		
Domain						
Physical health	7	0.59-0.84	3.99	57.0		
Psychological	6	0.60-0.80	3.13	52.2		
Social relationships	3	0.70-0.75	1.85	61.6		
Environment	8	0.62-0.72	3.65	44.6		

Note. N=395 respondents from the VVS community sample. Each scale was analysed separately.

The table shows that each domain was unidimensional, with all items loading on a single principal factor. The loading ranges were all satisfactory, and the eigenvalues were as expected, with the exception of the social domain, possibly a function of the small number of items within this domain. Given these properties, the proportion of explained variance was a little low, especially for the environment domain. Overall the results were very positive.

Internal consistency

Internal consistency is the degree to which items within a facet or domain are cohesive and homogeneous in content. Cronbach's alpha coefficient estimates the internal consistency of items (Cronbach, 1951): since alpha is a function of inter-item correlations and the number of items, the acceptable range of alphas is between 0.60-0.90. Table 4.4 presents the coefficient alphas for the four WHOQOL-BREF domains for the total, inpatient, outpatient and community (well) samples of the VVS data, and the total, depressed and non-depressed samples of the Australian LIDO data.

Table 4.4 Coefficient alphas for the Australian WHOQOL-BREF domains

WHOQOL-BREF Domain	Number of items	VVS Total N=996 α	Inpat n=266 α	Output $n=334$ α	Well n=395 α	LIDO Total N=518 α	Depress n=411 α	S Not dep $n=107$
Dl 1 b 1d								
Physical health	/	.87	.87	.87	.87	.86	.83	.83
Psychological	6	.81	.80	.83	.81	.83	.79	.76
Social relationships	3	.68	.58	.74	.68	.65	.60	.69
Environment	8	.81	.73	.80	.81	.81	.77	.74

Note. Inpat=VVS inpatient sample; Outpat=VVS outpatient sample; Well=VVS community sample; Depress=LIDO depressed sample; Not dep=LIDO non-depressed sample.

Using both the VVS and LIDO data across a range of samples, both 'well' and 'ill', all but one of the Cronbach's alphas were in the range of 0.60-0.90. These findings therefore indicate acceptable internal consistency for each of the four WHOQOL-BREF domains.

Compared with the other three domains, Cronbach's alphas were slightly lower for the Social Relationships domain. In particular, the alpha for the inpatient cohort of the VVS fell outside the acceptable range suggesting that for inpatients the three social items did not form a unidimensional scale. Although partly due to scale length – Cronbach's alpha is a function of scale length – this finding for the inpatient cohort is explained by the poor correlation between the two items measuring (i) a person's satisfaction with his/her sex life and (ii) satisfaction with the support received from friends; r=0.18. The correlation between these two items was r=0.27 for the population cohort and r=0.40 for the outpatient cohort of the VVS. Given that the correlation between (ii) and the third item, (iii) satisfaction with personal relationships was fairly consistent for all three cohorts (r=0.44 for the population cohort, r=0.48 for the outpatient cohort, and r=0.33 for the inpatient cohort) it seems likely that the difficulty was due to item (i), a person's satisfaction with his/her sex life. Although related to the overall assessment of satisfaction with support from friends (item iii), this was not related to their assessment of satisfaction with support from friends (item ii).

A similar pattern of results has been evidenced for other national versions of the WHOQOL-BREF. In an international field trial of the BREF, which compiled data from 24 WHOQOL centres representing 23 countries worldwide, Nelson and Lotfy (1999) found that Cronbach's alphas were consistently high for domains 1, 2 and 4 (mostly above 0.75), and slightly lower for domain 3 (in the range of 0.55-0.74). Nelson and Lotfy noted that the domain 3 statistic should be interpreted with caution since it is usually recommended that a minimum of four items be included. The international analyses and findings will be discussed further later in this chapter.

Test-retest reliability

In the LIDO study, the WHOQOL-BREF was re-administered to the 'non-depressed' control sample at 2-week follow-up, for the purposes of examining test-retest correlations. Table 4.5 shows test-retest correlations for the BREF domains and 'overall QOL' items.

Table 4.5

Test-retest correlations for the Australian WHOQOL-BREF domains and global items

WHOQOL-BREF	N	r
Domain		
Physical health	113	.858
Psychological	109	.831
Social relationships	108	.846
Environment	112	.832
Item		

Item 1: 'QOL'	114	.571
Item 2: 'health'	113	.675

Note. All correlations significant at p<.001. Statistical test:

Pearson correlations for domains; Spearman rho for individual items.

As shown in Table 4.5, the test-retest Pearson correlations were above 0.8 for each of the domains, indicating excellent test-retest reliability of the WHOQOL-BREF domains. The lower, albeit significant, Spearman rho correlations for Items 1 and 2 are to be expected for single item analyses.

Using the WHOQOL-BREF: population or individual use?

The WHOQOL instruments have been designed primarily for use at a population level; viz., in epidemiological or research studies, clinical trials etc. The test-retest reliability of individual items provides an indication of the appropriateness of using the instrument at an individual level; viz., for individual assessment. Cohen's Kappa (k; Cohen, 1960), which assesses the level of agreement between two separate observations of the same variable, was used to measure test-retest reliability of each of the WHOQOL-BREF items. High kappas, indicating good test-retest reliability of individual items and high reliability at the item level, would support the use of the instrument for individual assessment. The Kappa statistics are shown in Table 4.6.

As shown in Table 4.6, kappas were low for all items, ranging from .230-.618, suggesting a relatively high degree of error (low reliability) at the item level. These findings suggest that the WHOQOL-BREF is not appropriate for individual assessment. It is therefore recommended that the WHOQOL-BREF, and indeed all of the WHOQOL instruments, be used only for assessing QOL at a population level.

Table 4.6 Cohen's Kappas for each item of the Australian WHOQOL-BREF

WHOQOL Item	k
Item 1	.46
Item 2	.45
Item 3	.46
Item 4	.62

Item 5	.59
Item 6	.44
Item 7	.57
Item 8	.50
Item 9	.55
Item 10	.23
Item 11	.41
Item 12	.54
Item 13	.46
Item 14	.41
Item 15	.44
Item 16	.47
Item 17	.41
Item 18	.42
Item 19	.40
Item 20	.48
Item 21	.54
Item 22	.47
Item 23	.40
Item 24	.50
Item 25	.57
Item 26	.56

Note. N's range from 113-115. Discrepencies due to missing data. k=Kappa.

Construct validity

In both the VVS and LIDO studies, several other HRQoL instruments were administered in addition to the WHOQOL-BREF, enabling assessment of the construct validity of the WHOQOL-BREF. In the VVS, the SF-36, the AQoL, the EQ5D, the HUI3, and the 15D were administered to all participants. In the LIDO study, the SF-12 was administered to the depressed sample (n=437) at baseline. Each of these instruments is discussed briefly below.

The SF-36 is a health status profile instrument with eight health state dimensions: physical functioning, role physical, bodily pain, general health, vitality, social function, role emotional and mental health. These can be combined into two key health status measures—physical function (PCS index) and mental health (the MCS index). The MCS scale is reported to be superior to any of the SF-36 mental health dimensions (Ware, Kosinski et al, 1995). The Mental Health Index (MHI-5), a 5-item summative mental health scale, is another subset of the SF-36. Other aspects of HRQoL or health status are covered more lightly or are omitted from the instrument altogether (Ware, Snow et al. 1993). Each dimension is separately scored, using simple rating scale techniques. These data are then weighted such that they form scores on a 0–100 point scale. For computation of the PCS and MCS scale scores, each dimension score is weighted in a three-step process to produce a standardised T-score (where the population mean score is 50 ± 10) (Ware, Snow et al. 1993; Hayes, Sherbourne & Mazel, 1993). The SF-12 is an abbreviated form of the SF-36.

For the AQoL, the descriptive system comprises 15 items in five dimensions. Item responses are ordinal scales with four levels per item. The dimensions are illness, independent living,

social relationships, physical senses, and psychological wellbeing (Hawthorne, Richardson & Osborne, 1999). The utility weights were derived from an Australian population sample using time-trade off (TT0). During the calculation of the utility index, the illness dimension score is not used. A multiplicative function is used to combine the remaining four dimensions into the utility index (Hawthorne, Richardson et al. 2000).

The EQ5D (formerly the EuroQoL) consists of 5 items, each of which has 3 ordinal response levels. The items measure mobility, self-care, usual activities, pain/discomfort and anxiety/depression. The utility weights were obtained from a representative sample of the UK population, using the TTO. The utilities are computed using a regression model in which each item level is considered (Dolan, Gudex et al. 1995).

The HUI3 comprises 15 items. The number of item responses varies between 4–6; again at an ordinal level. Of the 15 items, 12 are used in the utility score and form 8 'attributes'. These were constructed to be what can be described as 'within the skin' attributes; that is, they focus upon disability and impairment rather than upon handicap (Hawthorne, Richardson, Day & McNeil, 2000). The attributes are vision, hearing, speech, ambulation, dexterity, emotion, cognition and pain. The utility weights were derived using a visual analog rating scale (VAS), the values of which were transformed based on valuations obtained from the standard gamble. The weights reflect those of the Canadian population. As with the AQoL, the HUI3 uses a multiplicative model for combining the attributes into the index score (Furlong, Torrance & Freeny, 1996; Furlong, Feeny et al. 1998)

The 15D consists of 15 items, and like the EQ5D each item represents a dimension. The 15D also focuses primarily on 'within the skin' dimensions, covering mobility, vision, hearing, breathing, sleeping, eating, speech, elimination, usual activities, mental function, discomfort & symptoms, depression, distress, vitality and sexual function. The weights used were from the adult Finnish population and were elicited using rating scales. The data were transformed using Torrance's formulae (Torrance, Boyle & Horwood, 1982) and the results interpreted as having utility properties (Sintonen, 1995).

Construct validity for the WHOQOL-BREF was investigated through correlational analysis using these instruments as the external standard. Since each of these instruments purport to measure HRQoL, high correlations support the construct validity of the WHOQOL-BREF. More specifically, some instruments purport to measure certain *aspects* of HRQoL as reflected in the separate WHOQOL domains, thus can be regarded as a 'gold standard' for that particular domain. Given their specific relevance, these correlations are highlighted and discussed in detail. All correlations are presented in Table 4.7.

Table 4.7 Correlations between scores on the Australian WHOQOL-BREF domains and global items and other measures of health related quality of life

	WHOQOL	-BREF				
	Domains				<u>Items</u>	
	Physical	Psycholog	Social	Environment	QOL	Health
VVS						
SF-36						
PCS	.58	.20	.10	.17	.19	.53
MCS	.54	.70	.42	.55	.49	.33
Utility instruments						
AQoL	.69	.62	.48	.46	.50	.54
EQ5D	.64	.47	.25	.36	.36	.43
HUI3	.68	.56	.33	.42	.49	.53
15D	.80	.64	.40	.47	.44	.58
LIDO						
SF-12						
PCS	.72**	.16*	.04	.30**	.35**	.54**
MCS	.22**	.58**	.43**	.32**	.30**	.24**
MHI-5	.30**	.61**	.40**	.41**	.36**	.26**

Note. For VVS data, all correlations are significant at p<.01. For the LIDO data, ** p<.001 *p<.01 Bold highlights correlations with 'gold standard' measures. For the VVS, N's range from 384-394 healthy respondents. For the LIDO study, N's range from 401-426 depressed patients. For both studies the discrepencies are due to missing data.

Domain correlations

The PCS index of the SF-36 and SF-12 can be regarded as a 'gold standard' for the physical domain of the WHOQOL-BREF, while both the MCS index and the MHI-5 can be regarded as 'gold standards' for the psychological domain of the WHOQOL-BREF. As shown in Table 4.7, based on both the VVS and LIDO data sets, scores on the physical domain correlated highly as expected with the PCS index, while scores on the psychological domain correlated highly with both the MCS index and the MHI-5. These correlations suggest construct validity evidence for the physical and psychological domains. In addition, scores on both the physical and psychological domains of the WHOQOL correlated substantially with the other instruments administered in the VVS, particularly the AQoL, the HUI3 and the 15D, providing further validity evidence for these two WHOQOL-BREF domains. The table shows that for each of the utility instruments, the physical domain was more highly correlated than the psychological domain. This was expected given that the 15D and HUI3 primarily measure 'within the skin' attributes, and that the EO5D has four items measuring functional capacity and just one item measuring a psychological state. The higher correlation bewteen the psychological domain and the AQoL can be explained by the greater emphasis in the AQoL on mental health state measurement.

None of the measures administered in either the LIDO or the VVS can be regarded as an acceptable 'gold standard' for the social relationships or environment domains of the WHOQOL. On the whole, correlations with other instruments were significant but moderate for both these domains, suggesting that these two domains and the other HRQoL

instruments are measuring different but related aspects of QOL. That it was the AQoL which had the highest correlation with the social domain might be attributed to the fact that the AQoL is the only utility instrument to have a social dimension.

Item correlations

Correlations for the two 'overall QOL' items are also shown in Table 4.7. First, the moderate correlation between item 1 (QOL) and the AQoL provides some indication of the construct validity of item 1 as a measure of overall quality of life. (This is consistent with the hypothesis that HRQoL is a function of met expectation. This also explains the moderate correlations between item 1 and the MCS and HUI3). However, all item 1 correlations were modest. For item 2, correlations with the PCS were moderate for both data sets, providing some validation of the 'satisfaction with health' item, and suggesting that it might relate particularly to *physical* health. Item 2 also correlated moderately with scores on the AQoL, the HUI3 and the 15D, providing further validation of this general health item.

Discriminant validity

The discriminant validity of the WHOQOL-BREF was assessed by analysing WHOQOL-BREF scores according to the health status of respondents. In the VVS, WHOQOL-BREF scores were compared for the inpatient (n=266), outpatient (n=334) and community (n=396) samples, using ANOVA. Results are presented in Table 4.8. In the LIDO study, WHOQOL-BREF scores were compared for the depressed (n=437; using baseline scores) and non-depressed samples (n=115; using T1 test-retest scores), using t-test. Results are presented in Table 4.9.

Table 4.8

Differences between VVS community, outpatient and inpatient samples in mean (SD) scores for the Australian WHOQOL-BREF domains and global items

	Community <i>n</i> =396	Outpatient <i>n</i> =334	Inpatient <i>n</i> =266	F	df	p
Domains						
Physical	79.00 (17.05)	61.47 (22.50)	51.55 (23.11)	150.44	2,980	<.01
Psychological	72.63 (14.16)	65.37 (18.03)†	64.04 (18.34)†	26.76	2,980	<.01
Social relationships	72.15 (18.53)	62.89 (23.53)†	63.36 (21.02)†	22.03	2,976	<.01
Environment	74.83 (13.72)	67.93 (16.81)†	66.99 (15.96)†	26.96	2,980	<.01
Items						
Item 1: 'QOL'	4.31 (.75)	3.87 (.91)	3.65 (1.01)	48.89	2,977	<.01
Item 2: 'health'	3.64 (.93)	2.88 (1.03)	2.62 (1.19)	89.01	2,983	<.01

Note. For consistency in interpretation, scores on item 2 (general health) have been reversed. Statistical test: ANOVA. † not statistically significant using Tukey HDS test. All other comparisons significant at p<.01.

As shown in Table 4.8, using the VVS data, highly significant differences between groups were found for all four domains and both individual items. More specifically, for the physical domain and for the two individual items the mean scores were ordinal with significant differences between all three groups as expected. For the psychological, social

and environment domains, there were no significant differences between the two patient groups. For these three domains, the community group showed higher quality of life than both the inpatient and outpatient groups.

Overall, these findings support the discriminant validity of the WHOQOL-BREF. The physical domain and the two global items appear to discriminate well across the full health spectrum, from 'well' to 'very ill'. While the psychological, social and environment domains likewise discriminate between people who are 'well' and those who are 'ill', they show a lack of discrimination at the bottom end of the spectrum. ie. between those who are 'ill' (outpatients) and those who are 'very ill' (inpatients).

Table 4.9

Differences between LIDO depressed and non-depressed respondents in mean (SD) scores for the Australian WHOQOL-BREF domains and global items

	Depressed	Non-depressed	t	df	p
Domains					
Physical	53.58	74.25	11.73	216	<.01
Psychological	50.34	69.83	13.49	226	<.01
Social relationships	50.29	67.58	7.53	533	<.01
Environment	55.75	73.60	12.74	231	<.01
Items					
Item 1: 'QOL'	3.29	4.27	13.33	262	<.01
Item 2: 'health'	2.87	3.66	7.87	202	<.01

Note. N's range from 429 to 437 for the depressed sample and from 110-115 for the healthy sample. Statistical test: Independent T-test. For domain 3, Levene's Test was not significant, therefore equal variances assumed.

As shown in Table 4.9, using the LIDO data, significant differences between groups were found for all four domains and both individual items. These findings demonstrate that the WHOQOL-BREF domains and items are highly sensitive to differences between depressed and non-depressed individuals.

Sensitivity to change

The sensitivity of the WHOQL-BREF to change was assessed through examination of differences between WHOQOL-BREF scores taken pre- and post-treatment for a subsample of depressed individuals from the LIDO study (n=26). One of the eligibility criteria for the LIDO study was that patients be untreated at the beginning of the study, hence baseline WHOQOL-BREF scores were used as the 'pre-treatment' measure. At 3 month follow-up, patients were asked if, in the previous three months, they had "been counseled or given medications for the treatment of depression". For those who had received treatment, 9 month follow-up scores were used as the 'post-treatment' measure. Paired t-tests (repeated measures design) were used to compare pre- and post-treatment scores for this group. Results are presented in Table 4.10.

Table 4.10 Differences between pre- and post-treatment mean (SD) scores for the Australian WHOQOL-BREF domains and global items

	N	Pre-treatment	Post-treatment	t	df	p
Domains						
Physical	33	42.86 (17.54)	52.81 (22.81)	11.25	32	<.01
Psychological	33	39.77 (17.71)	47.47 (19.15)	7.18	32	<.01
Social relationships	34	34.81 (26.94)	45.59 (23.50)	8.20	33	<.01
Environment	34	49.45 (18.03)	53.59 (17.58)	3.64	33	.065
Items						
Item 1: 'QOL'	34	2.82 (1.06)	3.32 (.91)	9.84	33	<.01
Item 2: 'health'	34	2.50 (1.02)	2.62 (1.13)	0.80	33	.379

Note. N=34 depressed patients from the LIDO study. Statistical test: dependent T-test.

As shown in Table 4.10, for each domain, the post-treatment score was substantially higher – indicating improved quality of life – following treatment for depression. The difference reached statistical significance for the physical, psychological and social relationships domains. Given the small sample size, these differences indicate that these three domains of the WHOQOL-BREF are highly sensitive to change following treatment for depression.

Pre- and post-treatment scores for items 1 and 2 are also shown in Table 4.10. The difference between pre- and post-treatment scores was significant for item 1 pertaining to general QOL, but not for item 2 pertaining to satisfaction with health. This could be explained by the fact that depression is a mental illness and that people may think of 'health' as having a more physical component: this interpretation is consistent with the higher correlation between this item and the SF-36 PCS summary scale when compared with the SC-36 MCS summary scale as presented in Table 4.7.

Conclusion

The analyses undertaken with both the VVS and LIDO data sets provide considerable validation of the Australian WHOQOL-BREF. Overall the instrument shows good factor structure. Each of the four domains appears to be both sensitive to the health status of respondents, and sensitive to change in health status following treatment. All four domains demonstrate good internal consistency and excellent test-retest reliability. The physical and psychological domains in particular also demonstrate good construct validity.

The two global items demonstrate moderate but acceptable test-retest reliability. The overall QOL item appears to be sensitive to change in health status following treatment, while both individual items show good discrimination between well, ill and very ill populations. These findings are encouraging in terms of the use of these items as overall indicators of overall QOL. However, the relatively low correlations with scores on other HRQoL instruments suggest that further evaluation of the construct validity of these two items is desirable before they can be confidently used as acceptable individual measures of QOL. Our advice to users of the WHOQOL-BREF is that while these two items provide additional information, they should not replace using the WHOQOL-BREF proper.

PSYCHOMETRIC PROPERTIES OF THE WHOQOL-BREF: INTERNATIONAL DATA

The psychometric properties of the WHOQOL-BREF have also been investigated internationally (Nelson & Lotfy, 1999). Using data from 23 countries (n=11,830), respondents were sampled from the general population and from primary care settings serving patients with physical and/or mental disorders. Just over half (53%) were women and slightly more were (57%) were married. Age ranged from 12 to 97 years with a mean of 45 (SD=16). Of those classified as "sick" (47%), most had physical disorders (35%) while 12% had mental disorders. Slightly more than half (53%) reported no ill health conditions.

On the basis of the global data, all domains demonstrated good *internal consistency*, with Cronbach's alphas of 0.82, 0.81, 0.68 and 0.80 for domains 1, 2, 3 and 4 respectively. The lower value for domain 3 might be attributable to the smaller number of constituent items. In terms of *discriminant validity*, 14 of 23 centres interviewed a community sample for comparison with the patient sample. Comparison of domain scores for the two cohorts demonstrated excellent discriminant validity across all domains, most notably domain 1. These and other global analyses, which indicate that the WHOQOL-BREF has good psychometric properties are discussed in detail in Nelson and Lotfy (1999).

ADMINISTRATION GUIDELINES

The WHOQOL-BREF was designed for self-administration, but can be interviewer-administered if necessary. Self-administration time for 'well' people who are literate in the relevant language is approximately 5 minutes. Interviewer-administration requires additional time: approximately 15 to 20 minutes.

Self-administration

Participants should be instructed to complete the WHOQOL-BREF in a quiet place, free from distractions and the influence of other people. Items should always be administered in the order in which they appear in the WHOQOL-BREF. The cover page, which gives brief instructions and an example of how to respond to the questions, should always be included. Demographic and health questions are NOT included in the WHOQOL-BREF, and need to be included as a separate demographic questionnaire.

Interviewer administration

Before beginning the questionnaire, the interviewer should read out the instructions provided on the front page of the WHOQOL-BREF, including the example item and responses. The interviewer can also give an estimation of the time the interview will take.

During the interview, the respondent should be made to feel comfortable enough to ask the interviewer to slow down, repeat a question, or speed up. The response options can be

repeated with each item. If appropriate, the respondent should have a copy of the questionnaire to follow, regardless of their ability to read.

As with the WHOQOL-100, interviewers administering the WHOQOL-BREF should be trained to minimise bias. Interviewers should never express their own opinions and should avoid giving cues in their language, vocal inflection, posture, and facial expressions. It should be explained to the respondent that there are no right or wrong answers. Interviewers should not explain questions: misunderstood items should simply be repeated, and respondents should be encouraged to interpret the questions in their own way. Any comments made by the interviewer should be recorded on the questionnaire, to enable identification of potential bias.

SCORING

The WHOQOL-BREF produces a profile with four domain scores and two individually scored items about an individual's overall perception of QOL and health (Q1 and Q2). The four domain scores are scaled in a positive direction, with a score range of 0-100, and with higher scores denoting higher QOL. So too, the two individual items assessing overall QOL are scaled in a positive direction, with a score range of 1-5, and with higher scores denoting higher QOL. Methods for obtaining domain scores are presented below. A computer diskette containing the necessary algorithms for computing domain scores, based on SPSS, is supplied together with this manual.

Calculating raw domain scores

Raw domain scores are calculated by straightforward summative scaling of constituent items. Three negatively-worded items need to be reverse-scored (Q3, Q4 and Q26), as shown in the formulae.

The raw domain scores are calculated as follows⁵:

 $\begin{array}{lll} \mbox{Physical health} = & (6-Q3) + (6-Q4) + Q10 + Q15 + Q16 + Q17 + Q18 \\ \mbox{Psychological health} = & Q5 + Q6 + Q7 + Q11 + Q19 + (6-Q26) \\ \mbox{Social relationships} = & Q20 + Q21 + Q22 \\ \mbox{Environment} = & Q8 + Q9 + Q12 + Q13 + Q14 + Q23 + Q24 + Q25 \\ \end{array}$

Because each domain comprises a different number of items, the upper and lower possible raw score and the overall raw score range differs for each domain. These values, which are required in calculating transformed scores, are shown in Table 4.11.

 4 Note correspondences between item numbers in the WHOQOL-BREF and the original item numbers from the WHOQOL-100: Q1=G1, Q2=G4, Q3=F1.4, Q4=F11.3, Q5=F4.1, Q6=F24.2, Q7=F5.3, Q8=F16.1, Q9=F22.1, Q10=F2.1, Q11=F7.1, Q12=F18.1, Q13=F20.1, Q14=F21.1, Q15=F9.1, Q16=F3.3, Q17=F10.3, Q18=F12.4, Q19=F6.3, Q20=F13.3, Q21=F15.3, Q22=F14.4, Q23=F17.3, Q24=F19.3, Q25=F23.3, Q26=F8.1.

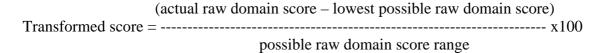
Table 4.11 Lower and upper raw values and possible raw score range for each of the domains of the Australian WHOQOL-BREF

D	omain	Lower value	Upper value	Possible score range	
1	Physical	7	35	28	
2	Psychological	6	30	24	
3	Social relationships	3	15	12	
4	Environment	8	40	32	

Transforming raw domain scores to 0-100 scale

Raw domain scores need to be transformed to a 0-100 scale, for ease of comparison with other data sets. This transformation converts the lowest possible score to zero and the highest possible score to 100. Scores between these values represent the percentage of the total possible score achieved. The values shown in Table 4.11 are used in calculating the transformed scores.

Raw scores are transformed using the following formula:



CHAPTER 5 - THE CHINESE-AUSTRALIAN WHOQOL-100

A culturally-relevant Chinese-Australian version of the WHOQOL-100 has been developed at the Melbourne Field Study Centre in collaboration with the Victorian Transcultural Psychiatry Unit and the Mental Health Research Institute of Victoria. The research team consisted of seven medical professionals, both English speaking and English/Chinese bilingual.

The Chinese-Australian WHOQOL-100 (CA-WHOQOL) was developed in accordance with the WHOQOL Protocol for New Centres (WHO, 1994). There were several phases involved: translation of the facet definitions and core questions; focus groups to assess the comprehensiveness of the translation and identify new aspects of QOL relevant to Chinese-Australian culture; the generation of new items; and field testing of the pilot version of the CA-WHOQOL. Throughout the developmental process, the CA-WHOQOL team liaised regularly with researchers in Hong Kong who were developing a Chinese-Hong Kong WHOQOL instrument. This chapter briefly outlines the phases in the development of the CA-WHOQOL. The developmental process and uses of the CA-WHOQOL are discussed in detail elsewhere (Gao, Murphy, Herrman, Minas, Pantalis & Gureje, 1997; Gao, Murphy, Herrman, Tan, Minas, Pantelis & Gureje, 1999). To date, a Chinese-Australian version of the shorter WHOQOL-BREF instrument has not been developed.

DESCRIPTION OF THE CHINESE-AUSTRALIAN WHOQOL-100

Like the English version, the CA-WHOQOL-100 is a 100-item self-administered instrument consisting of six domains: physical, psychological, level of independence, social relationships, environment, and spiritual. Again these domains contain 24 four-item facets, for a total of 96 items, with one additional facet (4 items) pertaining to global QOL and general health. Again objective, subjective and importance items are included, and a 5-point response scale is used. Scores can be obtained for each facet and domain, with high scores corresponding to a favorable QOL. A copy of the CA-WHOQOL-100 can be obtained upon request from the Melbourne WHOQOL Field Study Centre.

DEVELOPMENT OF THE CHINESE-AUSTRALIAN WHOQOL-100

Stage 1: Forward translation of the core WHOQOL questions

As a first step, items from the WHOQOL-100, together with the facet definitions, were translated into Chinese according to the agreed WHO translation process (Sartorius & Kuyken 1994; WHOQOL Group 1994). The major aim of the translation process was to achieve three types of equivalence between the two version: conceptual, semantic and technical equivalence (Sartorius & Kuyken, 1994). The process involved a twofold, blind forward translation, monolingual discussion of the Chinese version, back translation, and

bilingual discussion and comparison of the two English versions (the original and the back-translation).

The forward translation (into Chinese) was undertaken separately by both the main Chinese-speaking investigator and a professional translator. A meeting was held between the two translators to review and resolve the minor differences between the two Chinese versions.

The back translation (into English) was undertaken by a second professional translator who had not been involved in the forward translation. Discrepencies between the two versions were identified and resolved at a bilingual meeting of the CA-WHOQOL team. Once agreement was reached, a Chinese version of the 100 core WHOQOL items and each of the facet definitions was compiled for use in the focus group discussions.

Stage 2: Focus groups

Six focus groups were conducted. Two comprised Mandarin-speaking health professionals, two comprised Mandarin speaking health care users, and two comprised Cantonese speaking health care users. Mandarin and Cantonese are the two most widely used Chinese dialects in Australia (Gao et al. 1997). A total of 8 health professionals, 12 Mandarin speaking lay people and 15 Cantonese speaking lay people participated. Two separate focus group moderators were fluent in the relevant language and were trained according to the WHO Focus Group Moderators Training Procedures (WHO, 1992). The discussions were held in Mandarin or Cantonese. While participants were free to use English if they found their Chinese insufficient to express a specific point, this was rarely necessary. For each facet discussed, the aim of the discussion was to ascertain: a) whether participants regarded the facet as important to themselves/their patients; b) whether they understood the proposed WHOQOL items; c) whether the proposed WHOQOL items were adequate to address all the aspects of QOL; and d) what new items and/or facets were needed.

All of the core WHOQOL-100 items were regarded by focus group participants as relevant to the Chinese-Australian community. However, following the focus group work, it was clear that some aspects of QOL for Chinese-Australians were not adequately covered by the WHOQOL-100, and some not addressed at all. In the former case, new questions within an existing facet were needed. This applied in regard to four facets: pain and discomfort, positive feelings, negative feelings, and financial resources. In the latter case, new facets and their constituent items were needed. This applied in regard to two aspects of QOL: language and literacy, and respect and discrimination. The findings and implications of the focus group work are discussed in detail in Gao et al. (1997).

Stage 3: Item generation

A question-writing panel, consisting of the CA-WHOQOL study team, was convened. On the basis of the focus group transcripts, the panel developed new items and facets to reflect issues relevant to the QOL of the Chinese-Australian community but not addressed in the WHOQOL-100. Where possible, newly developed items retained the essence of the items suggested by focus group participants. All items were developed to meet the criteria for

WHOQOL items suggested by WHO. Items were generated in Chinese and translated into English only for the purpose of discussion by the CA-WHOQOL team. Again a process of twofold, blind forward and back translation was used. The newly-developed items (translated again into English) were reviewed by WHO, Geneva, for approval. Newly generated items were required to compete psychometrically with existing items before they were accepted by WHO.

Stage 4: Response scale derivation

Rather than directly translate the English response scales, culturally-relevant response scales were developed for the Chinese-Australian community, as is the case in all new centres. The same standardised method was employed for generating the response scales, as described earlier for the WHOQOL-100 (WHO 1993; WHOQOL Group, 1994). A list of at least 15 *possible* anchor point descriptors was generated for each question type and, using 100mm visual analogue scales marked with the standard (translated) end-points for each question type, a sample of native Chinese speakers from Melbourne (N=21) indicated where on the scale they felt each of the possible anchor points was situated in relation to the two end-points. The three intermediate descriptors were then chosen on the basis of their mean position, with the anchor points in the ranges of 20-30mm, 45-55mm and 70-80mm being selected. A bilingual review process was used to check on the comparability of the Chinese-Australian and English-Australian descriptors.

Stage 5: Compiling the CA-WHOQOL

The Chinese-Australian WHOQOL-100 (CA-WHOQOL) was compiled. The instrument comprised translated versions of the original WHOQOL-100 items plus newly generated items which met the criteria for WHOQOL items and were approved by WHO in Geneva. Four new items related to pre-existing facets: one new item for each of the facets pain and discomfort, positive feelings, negative feelings, and financial resources. Eight new items addressed the two newly identified WHOQOL facets: language and literacy, and respect and discrimination (4 items for each facet). In retaining the core WHOQOL-100 items, the CA-WHOQOL maintained cross-cultural comparability, a key aspect of all the WHOQOL instruments. At the same time, by also including new items, the CA-WHOQOL is culturally relevant for the Chinese-Australian community.

The newly generated CA items and facets are shown in Table 5.1.

Table 5.1

Newly generated CA facets and items

Facet	i	Item	
F1	Pain & discomfort	F1.5	To what extent do you have to endure pain and discomfort instead of seeking help or expressing it to others?
F4 F8	Positive feelings Negative feelings	F4.5 F8.5	Do you feel happy in your life? To what extent do you have to endure or hide negative feelings?

Financial resources Language & literacy	F18.5 F25.1	How able are you to save for the future? To what extent do you have language difficulties in communicating with others?
	F25.2	To what extent does language difficulty in reading and writing interfere with your daily activities?
	F25.3	To what extent does language difficulty inhibit your social life?
	F25.4	To what extent are you satisfied with your language abilities?
Respect &	F26.1	To what extent do you feel treated equally by others?
liscrimination	F26.2	To what extent do you feel discriminated against?
	F26.3	How well do you think you are esteemed by others?
	F26.4	To what extent to you feel looked down upon by others?
		F25.1 F25.2 F25.3 F25.4 Respect & F26.1 liscrimination F26.2 F26.3

The 112-item pilot CA-WHOQOL instrument was compiled using standardised formatting, instructions, headers and question order. All questions asked about "the last two weeks". On the whole, questions were grouped according to response scales, thus facilitating ease of completion. The newly derived Chinese-Australian response scales were applied to the instrument.

Stage 6: Field-testing

Following a standardised protocol, a field test of the pilot instrument was undertaken in Melbourne, with a target sample of 300 respondents (both patients and well people). The following is an outline of the Chinese Australian field-trial of the 112-item CA-WHOQOL instrument. The field-testing process is discussed in detail in Gao et al. (1999).

Sample and recruitment

A number of recruitment strategies were utilised in accessing a sample of Chinese-Australians. The methods included: accessing people through Chinese community organisations, approaching patients and their relatives in waiting rooms of general practice surgeries located in suburbs known to have a high Chinese population, and extracting names and addresses from the electronic telephone listings (using distinctive Chinese surnames). For the first two approaches, questionnaires were handed to respondents and either returned immediately on completion or mailed in a reply paid envelope when convenient. For the third approach, questionnaires were mailed to respondents and returned in reply-paid envelopes provided.

A total of 381 respondents completed the pilot CA-WHQOOL instrument. Just over half (55.4%) were male. Age ranged from 17 to 85 years, with a mean age of 42.04 years and a standard deviation of 11.26 years. Education level also varied with 4.5% primary education, 29.4% secondary, 52% college or university, and 11.8% postgraduate.

Analysis

Data analysis undertaken by WHO in Geneva and Edinburgh demonstrated that the new items and facets generated for the CA-WHOQOL were psychometrically satisfactory. The details and results of these analyses are discussed briefly below.

PSYCHOMETRIC PROPERTIES OF THE CHINESE-AUSTRALIAN WHOQOL-100

Factor structure

Principal Components Analysis identified 23 factors with eigenvalues greater than 1, explaining 71.4% of the variance. Two key findings supported the factor structure of the CA-WHOQOL. First, the four new CA items added to existing WHOQOL facets loaded with the expected factors. Second, items from the two new CA facets emerged as clear factors, independent from the existing WHOQOL factors, supporting their relevance as key issues in the QOL of Chinese-Australians. These findings suggest that the factor structure of

the CA-WHOQOL remained robust with the addition of the new facets and items. Table 5.2 shows the factor loadings relevant to the new facets and items.

Table 5.2 Factor loadings for the new CA facets and items

Factor	Item	Loading
Factor 6	F8.1 F8.3 F8.2 F8.5* F10.4 F8.1	.780 .755 .700 .636 .549
Factor 7	F25.1* F25.3* F25.4* F25.2* F20.1	.863 .845 .818 .703 .456
Factor 9	F18.2 F18.1 F18.3 F18.5* F18.1	.741 .705 .649 .640
Factor 10	F1.4 F1.2 F1.3 F1.1 F1.5* F18.1	.718 .674 .651 .640 .476 .440
Factor 15	F26.4* F26.2* F26.1* F26.3*	.786 .773 .622 .544
Factor 17	F4.3 F4.1 F4.5* F4.4	.592 .524 .516 .470

Note. For clarity, the information presented is restricted to new facets and items. * indicates new CA items.

Internal consistency of facets

Cronbach's alphas were calculated for the two new facets, as an indication of the internal consistency of the facets. Both of the new facets had high Cronbach's alphas (α =0.93 for language and literacy; α =0.87 for respect and discrimination), indicating excellent internal consistency.

For the four 5-item facets, where a new CA item was added to the original four items, Cronbach's alphas were all above 0.8, again indicating excellent internal consistency. Further analyses explored the effect on Cronbach's alphas of exclusion of the new items. As shown in Table 5.3, on excluding the new items, the internal consistencies were reduced for two of the facets and remained the same for two of the facets. These findings further support the internal consistency of the new CA facets.

Table 5.3 Changes in Cronbach's alpha after excluding new CA items

New item	Facet α with item included	Facet α with item excluded
F1.5	0.84	0.84
F4.5	0.85	0.79
F8.5	0.87	0.87
F18.5	0.87	0.86

All but four of the other original facets had alphas above 0.70, indicating good internal consistency. The remaining four facets had alphas above 0.60.

The CA-WHOQOL has been developed to reflect the cultural factors influencing the QOL of Chinese-Australians. Chinese traditional values such as tolerance, frugality and valuing other people's opinions were embodied in the newly developed facets and items. The immigrant status of Chinese-Australians also affects their QOL. On the whole, the psychometric properties of the CA-WHOQOL supports its reliability as a measure of QOL for Chinese-Australians.

ADMINISTRATION GUIDELINES

The CA-WHOQOL was designed for self-administration, but can be interviewer-administered if necessary. The WHOQOL co-ordinating group suggests that self-administration time for 'well' people who are literate in the relevant language is between 20 and 30 minutes. Interviewer-administration requires additional time: 40 to 90 minutes according to the WHOQOL co-ordinating group.

Self-administration

Participants should be instructed to complete the CA-WHOQOL in a quiet place, free from distractions and influences from other people. Items should always be administered in the order in which they appear in the CA-WHOQOL. The cover page, which gives brief instructions and an example of how to respond to the questions, should always be included. Questions regarding respondents' demographic and health details are included on the final

page of the CA-WHOQOL and should be administered together with the major questions, unless these items are incorporated into a separate demographic questionnaire.

Interviewer administration

Before beginning the questionnaire, the interviewer should read out the instructions provided on the front page of the CA-WHOQOL, including the example item and responses. The interviewer can also give an estimation of the time the interview will take.

During the interview, the respondent should be made to feel comfortable enough to ask the interviewer to slow down, repeat a question, or speed up. The response options can be repeated with each item. For long lists of items, the lead-in can be repeated periodically so that the respondent is reminded of the meaning of the response options. By way of encouragement, the interviewer can inform the respondent when they are halfway through the questionnaire. If appropriate, the respondent should have a copy of the questionnaire to follow along, regardless of their ability to read.

Interviewers should be trained to minimise bias. Interviewers should never express their own opinions and should avoid giving cues in their language, vocal inflection, posture, and facial expressions. Even apparently encouraging expressions such as smiling and nodding can introduce bias into the responses and need to be avoided. Interviewers should not explain questions: misunderstood items should simply be repeated, and respondents should be encouraged to interpret the questions in their own way. Any comments made by the interviewer should be recorded on the questionnaire, to enable identification of potential bias.

SCORING

The CA-WHOQOL produces a QOL profile. It is possible to derive (a) 26 individual facet scores; (b) six domain scores; and (c) general QOL and health perceptions scores (based on the four questions pertaining to global QOL and general health). The 26 facet scores denote the individual's evaluation of his/her functioning in the particular area of life addressed by that facet. The six domain scores denote an individual's perception of QOL in each particular QOL domain. The CA-WHOQOL is scored through straightforward summative scaling, with item score-reversal where necessary.

Facet scores

Facet scores are obtained by summing scores for the four or five constituent items from that facet. Several facets contain items which need to be reverse-scored before facet scores are calculated, using the formula "x(rev)=6-x".

The formulae for calculating facet scores are as follows:

Overall QOL and General Health = G1 + G2 + G3 + G4

```
Facet 1 (F1) = F1.1 + F1.2 + F1.3 + F1.4 + F1.5
Facet 2 (F2) = F2.1 + (6-F2.2) + F2.3 + (6-F2.4)
Facet 3 (F3) = F3.1 + (6-F3.2) + F3.3 + (6-F3.4)
Facet 4 (F4) = F4.1 + F4.2 + F4.3 + F4.4 + F4.5
Facet 5 (F5) = F5.1 + F5.2 + F5.3 + F5.4
Facet 6 (F6) = F6.1 + F6.2 + F6.3 + F6.4
Facet 7 (F7) = F7.1 + (6-F7.2) + (6-F7.3) + F7.4
Facet 8 (F8) = F8.1 + F8.2 + F8.3 + F8.4 + F8.5
Facet 9 (F9) = F9.1 + F9.2 + (6-F9.3) + (6-F9.4)
Facet 10 (F10) = F10.1 + (6-F10.2) + F10.3 + (6-F10.4)
Facet 11 (F11) = F11.1 + F11.2 + F11.3 + F11.4
Facet 12 (F12) = F12.1 + F12.2 + F12.3 + F12.4
Facet 13 (F13) = (6-F13.1) + F13.2 + F13.3 + F13.4
Facet 14 (F14) = F14.1 + F14.2 + F14.3 + F14.4
Facet 15 (F15) = F15.1 + F15.2 + F15.3 + (6-F15.4)
Facet 16 (F16) = F16.1 + F16.2 + (6-F16.3) + F16.4
Facet 17 (F17) = F17.1 + F17.2 + F17.3 + F17.4
Facet 18 (F18) = F18.1 + (6-F18.2) + F18.3 + (6-F18.4) + F18.5
Facet 19 (F19) = F19.1 + F19.2 + F19.3 + F19.4
Facet 20 (F20) = F20.1 + F20.2 + F20.3 + F20.4
Facet 21 (F21) = F21.1 + F21.2 + F21.3 + F21.4
Facet 22 (F22) = F22.1 + (6-F22.2) + F22.3 + F22.4
Facet 23 (F23) = F23.1 + (6-F23.2) + F23.3 + (6-F23.4)
Facet 24 (F24) = F24.1 + F24.2 + F24.3 + F24.4
Facet 25 (F25) = (6-F25.1) + (6-F25.2) + (6-F25.3) + F25.4
Facet 26 (F26) = F26.1 + (6-F26.2) + F26.3 + (6-F26.4)
```

Table 5.4 shows the direction of scaling for each facet and constituent reverse-scored items. For the 23 positively-framed facets, scores are scaled in a positive direction (ie. higher scores indicate higher QOL). For the three negatively-framed facets, scores are scaled in a negative direction (and will be reverse-scored in calculating domain scores).

Table 5.4 Direction of scaling and reverse-scored items for each facet of the CA-WHOQOL

Facet		Direction of scaling	Reverse-scored items
Over	all QOL and General health	+	none
F1	Pain and discomfort	-	none
F2	Energy and fatigue	+	F2.2 and F2.4
F3	Sleep and rest	+	F3.2 and F3.4
F4	Positive feelings	+	none
F5	Thinking, learning, memory & concentration	+	none
F6	Self-esteem	+	none
F7	Body image and appearance	+	F7.2 and F7.3
F8	Negative feelings	-	none
F9	Mobility	+	F9.3 and F9.4

F10	Activities of daily living	+	F10.2 and F10.4
F11	Dependence on medication or treatment	-	none
F12	Working capacity	+	none
F13	Personal relationships	+	F13.1
F14	Social support	+	none
F15	Sexual activity	+	F15.4
F16	Physical safety & security	+	F16.3
F17	Home environment	+	none
F18	Financial resources	+	F18.2 and F18.4
F19	Health and social care:availability & access	+	none
F20	Opportunities for acquiring new info & skills	+	none
F21	Participation in & opportunity for recreation	+	none
F22	Physical environment: pollution/noise etc	+	F22.2
F23	Transportation	+	F23.2 and F23.4
F24	Spirituality/religion/personal beliefs	+	none
F25	Language and literacy	+	F25.1, F25.2 and F25.3
F26	Respect and discrimination	+	F26.2 and F26.4

Adjustment of facet scores to ensure comparability with Australian WHOQOL-100 data In order to be comparable with facet scores of the Australian WHOQOL-100, or with other standard WHOQOL-100 instruments, four of the CA-WHOQOL facet scores need to be adjusted. This adjustment is also necessary if facet scores are to be used in calculating domain scores. This formula applies to facets 1, 4, 8 and 18 (Pain and discomfort, positive feelings, negative feelings, and financial resources), each of which have five instead of the regular four items (due to the addition of a newly developed CA item).

Raw scores for facets 1, 4, 8 and 18 are adjusted using the following formula:

Adjusted facet score = actual raw facet score x .80

Transformation of facet scores to 0-100 Scale (optional)

While not commonly necessary, facet scores can be transformed to a 0-100 scale, for ease of comparison with other data sets. This transformation converts the lowest possible score to zero and the highest possible score to 100. Scores between these values represent the percentage of the total possible score achieved. In transforming scores to a 0-100 scale, use the adjusted scores for facets 1, 4, 8 and 18 (see above). Following adjustment, all facet scores range from 4-20, with a possible score range of 16.

Raw scores are transformed using the following formula:

Domain scores

Domain scores are obtained by summing scores on the relevant facets, including F1 to F24. (Facets 25 and 26 do not contribute to domain scores). Because the six domains contain different numbers of facets, the summative score needs to be divided by the number of facets contained in that domain, in order to achieve comparability across domains. All domain scores are scaled in a positive direction (ie. higher scores denote higher QOL). As such, negatively-framed facets need to be reverse-scored during calculation of domain scores, as shown in the formulae. In order to be comparable with domain scores of the Australian WHOQOL-100 or other versions of the WHOQOL-100, adjusted facet scores (for facets 1, 4, 8 and 18) should be used in calculating domain scores. All domain scores range from 4-20. *denotes adjusted facet scores.

The formulae for calculating domain scores from facet scores are as follows:

Physical domain =
$$(24-F1*score) + F2 score + F3 score$$

Psychological domain =
$$\frac{\text{F4* score} + \text{F5 score} + \text{F6 score} + \text{F7 score} + (24-\text{F8* score})}{5}$$

Level of independence domain =
$$\underline{F9 \text{ score} + F10 \text{ score} + (24-F11 \text{ score}) + F12 \text{ score}}$$

Social relationships domain =
$$\frac{F13 \text{ score} + F14 \text{ score} + F15 \text{ score}}{3}$$

Spiritual domain = F24 score

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APPENDIX I: Australian WHOQOL-100

WORLD HEALTH ORGANISATION QUALITY OF LIFE

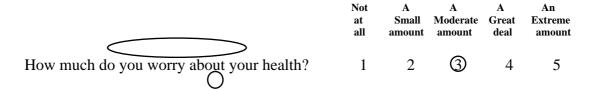
THE WHOQOL-100 Australian Version (May 2000)

Instructions

This questionnaire asks how you feel about your quality of life, health, and other areas of your life. Please answer <u>ALL</u> the questions. If you are unsure about which response to give a question, please choose the one that appears most appropriate. **You do not need to spend a lot of time on any questions: initial reactions are usually best**.

Please keep in mind your standards, hopes, pleasures, and concerns. We ask that you **think** about your life in the <u>last two weeks</u>.

For example, thinking about the last two weeks, a question might ask:



You should **circle the number that best fits** how often you have worried about your health over the **last two weeks**. So you would circle the number 4 if you worried about your health a lot, or number 1 if you have not worried about your health at all. Please read each question, assess your feelings, and circle the number on the scale for each question that best fits for you.

There are one hundred questions and **questions are listed on both** sides of the page.

The following questions ask about $\underline{\text{how much}}$ you have experienced certain things $\underline{\text{in the last two weeks}}$. For each question $\underline{\text{circle}}$ the number that best fits your situation.

		Not at all	A Small amount	A Moderate amount	A Great deal	An Extreme amount
1.	How much do you worry about your pain or discomfort?	1	2	3	4	5
2.	To what extent do you feel that physical pain prevents you from doing what you need to do?	1	2	3	4	5
3.	Do you have any difficulties with sleeping?	1	2	3	4	5
4.	How much do any sleep problems worry you?	1	2	3	4	5
5.	How much do you enjoy life?	1	2	3	4	5
6.	How much do you experience positive feelings in your life?	1	2	3	4	5
7.	How much do you value yourself?	1	2	3	4	5
8.	How much confidence do you have in yourself?	1	2	3	4	5
9.	Is there any part of your appearance which makes you feel uncomfortable?	1	2	3	4	5
10.	How much do any feelings of sadness or depression interfere with your everyday functioning?	1	2	3	4	5
11.	How much do any feelings of depression bother you?	1	2	3	4	5
12.	To what extent do you have difficulty in performing your routine activities?	1	2	3	4	5
13.	How much are you bothered by any limitations in performing everyday living activities?	1	2	3	4	5
14.	How much do you need any medication to function in your daily life?	1	2	3	4	5
15.	How much do you need any medical treatment to function in your daily life?	1	2	3	4	5

		Not at all	A Small amount	A Moderate amount	A Great deal	An Extreme amount
16.	To what extent does your quality of life depend on the use of medical substances or medical aids?	1	2	3	4	5
17.	How much do you like it where you live?	1	2	3	4	5
18.	How much do you worry about your safety and security?	1	2	3	4	5
19.	Do you have financial difficulties?	1	2	3	4	5
20.	How much do you worry about money?	1	2	3	4	5
21.	How much do you enjoy your free time?	1	2	3	4	5
22.	How concerned are you with the noise in the area you live in?	1	2	3	4	5
23.	To what extent do you have problems with transport?	1	2	3	4	5
24.	How much do difficulties with transport restrict your life?	1	2	3	4	5
		Not				
		at all	Slightly	Moderately	Very	Extremely
25.	How difficult is it for you to handle any pain or discomfort?	1	2	3	4	5
26.	How easily do you get tired?	1	2	3	4	5
27.	How much are you bothered by fatigue?	1	2	3	4	5
28.	How positive do you feel about the future?	1	2	3	4	5
29.	How well are you able to concentrate?	1	2	3	4	5
30.	Do you feel inhibited by your looks?	1	2	3	4	5
31.	How worried do you feel?	1	2	3	4	5
32.	How alone do you feel in your life?	1	2	3	4	5

		Not at all	Slightly	Moderately	Very	Extremely
33.	How well are your sexual needs fulfilled?	1	2	3	4	5
34.	Are you bothered by any difficulties in your sex life?	1	2	3	4	5
35.	How safe do you feel in your daily life?	1	2	3	4	5
36.	Do you feel you are living in a safe and secure environment?	1	2	3	4	5
37.	How comfortable is the place where you live?	1	2	3	4	5
38.	How easily are you able to get good medical care?	1	2	3	4	5
39.	How healthy is your physical environment (e.g., pollution, climate, noise, attractiveness)?	1	2	3	4	5

The following questions ask about <u>how completely</u> you experience or were able to do certain things in <u>the last two weeks</u>. For each question <u>circle</u> the number that best fits your situation.

		Not at all	Slightly	Somewhat	To a great extent	Completely
40.	Do you have enough energy for everyday life?	1	2	3	4	5
41.	Are you able to accept your bodily appearance?	1	2	3	4	5
42.	How well are you able to carry out your daily activities?	1	2	3	4	5
43.	How dependent are you on medications?	1	2	3	4	5
44.	Do you get the kind of support from others that you need?	1	2	3	4	5
45.	To what extent can you count on your friends when you need them?	1	2	3	4	5
46.	To what degree does the quality of your home meet your needs?	1	2	3	4	5
47.	Have you enough money to meet your needs?	1	2	3	4	5
48.	How available to you is the information you need in your daily life?	1	2	3	4	5

Go to the \underline{next} sheet >

		Not at all	Slightly	Somewhat	To a great extent	Completely
49.	To what extent do you have opportunities for acquiring the information that you feel you need?	1	2	3	4	5
50.	To what extent do you have the opportunity for leisure activities?	1	2	3	4	5
51.	How much are you able to relax and enjoy yourself?	1	2	3	4	5
52.	To what extent do you have adequate means of transport?	1	2	3	4	5

The following questions ask about <u>how satisfied, happy, or good</u> you have felt about various aspects of your life over <u>the last two weeks</u>. For each question <u>circle</u> the number that best fits your situation.

		Very Dissatisfie d	Fairly Dissatisfied	Neither Satisfied nor Dissatisfied	Satisfied	Very Satisfied
53.	How satisfied are you with the quality of your life?	1	2	3	4	5
54.	In general, how satisfied are you with your life?	1	2	3	4	5
55.	How satisfied are you with your health?	1	2	3	4	5
56.	How satisfied are you with your energy level?	1	2	3	4	5
57.	How satisfied are you with your sleep?	1	2	3	4	5
58.	How satisfied are you with your ability to learn new information?	1	2	3	4	5
59.	How satisfied are you with your ability to make decisions?	1	2	3	4	5
60.	How satisfied are you with yourself?	1	2	3	4	5
61.	How satisfied are you with your abilities?	1	2	3	4	5
62.	How satisfied are you with the way your body looks?	1	2	3	4	5
63.	How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5

Turn to the <u>back</u> of this page >

		Very Dissatisfie d	Fairly Dissatisfied	Neither Satisfied nor Dissatisfied	Satisfied	Very Satisfied
64.	How satisfied are you with your personal relationships?	1	2	3	4	5
65.	How satisfied are you with your sex life?	1	2	3	4	5
66.	How satisfied are you with the support you receive from your family?	1	2	3	4	5
67.	How satisfied are you with the support you receive from your friends?	1	2	3	4	5
68.	How satisfied are you with your ability to provide for or support others?	1	2	3	4	5
69.	How satisfied are you with your physical safety and security?	1	2	3	4	5
70.	How satisfied are you with your living conditions?	1	2	3	4	5
71.	How satisfied are you with the amount of money you have?	1	2	3	4	5
72.	How satisfied are you with your access to health services?	1	2	3	4	5
73.	How satisfied are you with the social care services?	1	2	3	4	5
74.	How satisfied are you with your opportunities to acquire new skills?	1	2	3	4	5
75.	How satisfied are you with your opportunities to learn new information?	1	2	3	4	5
76.	How satisfied are you with the way you spend your spare time?	1	2	3	4	5
77.	How satisfied are you with your physical environment (e.g., pollution, climate, noise, attractiveness)?	1	2	3	4	5
78.	How satisfied are you with the climate in the area where you live?	1	2	3	4	5
79.	How satisfied are you with your transport?	1	2	3	4	5

		Neither		
Very		Happy nor	Fairly	Very
Unhappy	Unhappy	Unhappy	Happy	Happy

80. How happy do you feel about your relationship with your family members?

Go to the <u>next</u> sheet >

		Very Poor	Poor	Neither Poor nor Good	Good	Very Good
81.	How would you rate your overall quality of life?	1	2	3	4	5
82.	How would you rate your sex life?	1	2	3	4	5
83.	How well do you sleep?	1	2	3	4	5
84.	How would you rate your memory?	1	2	3	4	5
85.	How would you rate the quality of social services available to you?	1	2	3	4	5

The following questions refer to <u>how often</u> you have felt or experienced certain things over the <u>last two weeks</u>. For each question <u>circle</u> the number that best fits your situation.

	Never	Infrequently	Sometimes	Frequentl y	Always
86. How often do you suffer physical pain?	1	2	3	4	5
87. Do you generally feel content?	1	2	3	4	5
88. How often do you have negative feelings, such as blue mood, despair, anxiety, depression?	1	2	3	4	5

The following questions refer to <u>any work you do</u>. Work here means any major activity you do. This includes voluntary work, studying full-time, taking care of the home, taking care of children, or unpaid work. So work, as it is used here, means the activities you feel take up a major part of your time and energy. Questions refer to the <u>last two weeks</u>.

		Not at all	Slightly	Somewhat	To a great extent	Completely
89.	Are you able to work?	1	2	3	4	5
90.	Do you feel able to carry out your duties?	1	2	3	4	5
		Very Dissatisfie d	Fairly Dissatisfied	Neither Satisfied nor Dissatisfied	Satisfied	Very Satisfied
91.	How satisfied are you with your capacity for work?	1	2	3	4	5

		Very Poor	Poor	Neither Poor nor Good	Good	Very Good
92.	How would you rate your ability to work?	1	2	3	4	5

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The next few questions ask about <u>how well</u> you were <u>able to move</u> <u>around</u> in the <u>last two weeks</u>. This refers to your physical ability to move your body in such a way as to allow you to move about and do the things you would like to do, as well as the things that you need to do.

		Not at all	Slightly	Moderately	Very	Extremely
93.	How well are you able to get around physically?	1	2	3	4	5
		Not at all	A Small amount	A Moderate amount	A Great deal	An Extreme amount
94.	How much do any difficulties in mobility bother you?	1	2	3	4	5
95.	To what extent do any difficulties in movement affect your way of life?	1	2	3	4	5
96.	How satisfied are you with your ability to move around?	1	2	3	4	5

The following questions are concerned with your **personal beliefs**, and how these affect your quality of life. These questions refer to **religion**, **spirituality**, **and other beliefs** you may hold. Once again these questions refer to the **last two weeks**.

		Not at all	A Small amount	A Moderate amount	A Great deal	An Extreme amount
97.	Do your personal beliefs give meaning to your life?	1	2	3	4	5
98.	To what extent do your personal beliefs give you the strength to face difficulties?	1	2	3	4	5
		Not at all	Slightly	Moderately	Very	Extremely
99.	To what extent do you feel your life to be meaningful?	1	2	3	4	5
100	To what extent do your personal beliefs help you to understand difficulties in life?	1	2	3	4	5

Go to the <u>next</u> sheet >

ABOUT YOU

1. What is your sex?	1 2	Male Female
2. What is your date of birth?		Date Month Year
3. What is your highest level of e	ducation	•
,	1	None at all
	2	Primary school
	3	Secondary school
	4	Apprenticeship
	5	University or college
	6	Post-graduate
4. What is your marital status?	1	Single
•	2	Married/defacto
	3	Separated
	4	Divorced
	5	Widowed
5. Are you currently ill?	1	Yes
3. The you currently in:	2	No
6. If yes, what is your diagnosis?		
7. Which of these income categor household, from all sources?	ries come	s closest to the total yearly income for your
	1	Under \$5,000
	2	\$5,000 to \$9,999
	3	\$10,000 to \$14,999
	4	\$15,000 to \$24,999
	5	\$25,000 to \$34,999
	6	\$35,000 to \$49,999
	7	\$50,000 to \$74,999
	8	\$75,000
(If all you know is your m	onthly in	come, please write it here)

THE END

APPENDIX II: Importance items

WORLD HEALTH ORGANISATION QUALITY OF LIFE

WHOQOL-100 IMPORTANCE QUESTIONS Australian Version (May 2000)

Instructions

The following questions ask about **how important** various aspects of your life are to you. We ask that you think about how much these affect your quality of life. For example, one question asks about how important sleep is to you. If sleep is not important to you, circle the number under "not important". If sleep is very important but not extremely important, you should circle the number under "very important". Unlike earlier questions, these questions **do not** refer only to the last two weeks.

		Not important	Neither important nor unimportant	Important	Very important	Extremely important
1.	How important to you is your overall quality of life?	1	2	3	4	5
2.	How important to you is your health?	1	2	3	4	5
3.	How important to you is it to be free of any pain?	1	2	3	4	5
4.	How important to you is having energy?	1	2	3	4	5
5.	How important to you is restful sleep?	1	2	3	4	5
6.	How important to you is it to feel happiness and enjoyment of life?	1	2	3	4	5
7.	How important to you is it to feel content?	1	2	3	4	5
8.	How important to you is it to feel hopeful?	1	2	3	4	5
9.	How important to you is being able to think through everyday problems and make decisions?	1	2	3	4	5

10. How important to you is being able to concentrate?	1	2	3	4	5
11. How important to you is feeling positive about yourself?	1	2	3	4	5
	Not important	Now tu Neither important nor unimportant		Very	Extremely
12. How important to you is your body image and appearance?	1	2	3	4	5
13. How important to you is it to be free of negative feelings (sadness, depression, anxiety, worry)?	1	2	3	4	5
14. How important to you is it to be able to move around?	1	2	3	4	5
15. How important to you is being able to take care of your daily living activities (washing, dressing, eating)?	1	2	3	4	5
16. How important to you is it to be free of dependence on medicines or treatments?	1	2	3	4	5
17. How important to you is being able to work?	1	2	3	4	5
18. How important to you are relationships with other people?	1	2	3	4	5
19. How important to you is support from others?	1	2	3	4	5
20. How important to you is your sexual life?	1	2	3	4	5
21. How important to you is feeling physically safe and secure?	1	2	3	4	5
22. How important to you is your home environment?	1	2	3	4	5
23. How important to you are your financial resources?	1	2	3	4	5
24. How important to you is being able to get adequate health care?	1	2	3	4	5
25. How important to you is being able to get adequate social help?	1	2	3	4	5
26. How important to you are chances for getting new information and knowledge?	1	2	3	4	5
27. How important to you are chances to learn new skills?	1	2	3	4	5

28. How important to you is relaxation or leisure?	1	2	3	4	5
29. How important to you is your environment (pollution, climate, noise, attractiveness)?	1	2	3	4	5
30. How important to you is adequate transport in your everyday life?	1	2	3	4	5
31. How important to you are your personal beliefs?	1	2	3	4	5

THE END

APPENDIX III: Australian WHOQOL-BREF

WORLD HEALTH ORGANISATION QUALITY OF LIFE

WHOQOL-BREF Australian Version (May 2000)

Instructions		

This assessment asks how you feel about your quality of life, health, and other areas of your life. Please answer all the questions. If you are unsure about which response to give a question, please choose the one that appears most appropriate. This can often be your first response.

Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life in the <u>last two weeks</u>.

Example:				0		
	Not at all	Slightly	Moderately	Very	Completely	
You would circle the number 4 if in from others	the last tw	o weeks	you got a gr	eat deal	l of support	
	Not at all	Slightly	Moderately	Very	Completely	
Do you get the kind of support from others that you need?	1	2	3	4	5	
but if you did not get any of the support from others that you needed in the last two weeks you would circle 1.						

Thank you for your help.

Now turn to the <u>back</u> of this page >

Please read each question and assess your feelings, for the last two weeks, and circle the number on the scale for each question that gives the best answer for you.

	Very poor	Poor	Neither Poor nor Good	Good	Very Good	
1. How would you rate your quality of life?	1	2	3	4	5	
	Very Dissatisfied	Fairly Dissatisfied	Neither Satisfied nor Dissatisfied	Satisfied	Very Satisfied	
2. How satisfied are you with your health?	1	2	3	4	5	
The following questions ask about how much you have experienced certain things in the <u>last two weeks.</u>						
	Not at all	A Small amount	A Moderate amount	A great deal	An Extreme amount	
3. To what extent do you feel that physical pain prevents you from doing what you need to do?	1	2	3	4	5	
4. How much do you need any medical treatment to function in your daily life?	1	2	3	4	5	
5. How much do you enjoy life?	1	2	3	4	5	
6. To what extent do you feel your life to be meaningful?	1	2	3	4	5	
	Not at all	Slightly	Moderately	Very	Extremely	
7. How well are you able to concentrate?	1	2	3	4	5	
8. How safe do you feel in your daily life?	1	2	3	4	5	
9. How healthy is your physical environment?	1	2	3	4	5	
	Not at all	Slightly	Somewhat	To a great extent	Completely	
10.Do you have enough energy for every day life	fe? 1	2	3	4	5	
11. Are you able to accept your bodily appearance?	1	2	3	4	5	
12. Have you enough money to meet your needs?	1	2	3	4	5	
13. How available to you is the information you need in your daily life?	1	2	3	4	5	

14. To what extent do you have the opportunity for leisure activities?

1 2 3 4 5

	Not at all	Slightly	Moderately	Very	Extremely
15. How well are you able to get around physically?	1	2	3	4	5

Go to the \underline{next} sheet >

The following questions ask you to say how good or satisfied you have felt about various aspects of your life over the <u>last two weeks</u>.

	Very Dissatisfied	Fairly Dissatisfied	Neither Satisfied nor Dissatisfied	Satisfied	Very Satisfied
16. How satisfied are you with your sleep?	1	2	3	4	5
17. How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
18. How satisfied are you with your capacity for work?	1	2	3	4	5
19. How satisfied are you with yourself?	1	2	3	4	5
20. How satisfied are you with your personal relationships?	1	2	3	4	5
21. How satisfied are you with your sex life?	1	2	3	4	5
22. How satisfied are you with the support you get from your friends?	1	2	3	4	5
23. How satisfied are you with the conditions of your living place?	1	2	3	4	5
24. How satisfied are you with your access to health services?	1	2	3	4	5
				4	5

	Never	Infrequently	Sometimes	Frequently	Always
26. How often do you have negative feelings such as blue mood, despair, anxiety,	1	2	3	4	5
depression?					

THE END